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ABSTRACT

This U.S. Department of Education, Division of Adult Education and Literacy (DAEL) symposium was designed to engage health and adult education practitioners in dialogues regarding strategies to help older adults with limited basic skills and their families to communicate more effectively with their health care providers. This volume summarizes the symposium's presentations and contains relevant accompanying materials. Section 1 is an introduction. Section 2 contains DAEL's letter introducing the symposium, a summary of the opening remarks, and the symposium agenda. Section 3 includes summaries of each presentation, and Section 4 summarizes a plenary discussion of key issues. Appendices include presenters' biographies, a complete list of participants, lists of members of committees that helped plan the symposium, and slides to complement the summaries in section 3. (Adjunct ERIC Clearinghouse for ESL Literacy Education) (KFT)

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# Health Literacy: Implications for Seniors Symposium Proceedings

August 1-2, 2001
Washington, D.C.

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Division of Adult Education and Literacy
Office of Vocational and Adult Education
U.S. Department of Education

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# Health Literacy: Implications for Seniors
## Symposium Proceedings

August 1-2, 2001
Washington, D.C.

October 2001

Prepared by
Daniel A. Levine
RTI International

Submitted to
Division of Adult Education and Literacy
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- A. Presenter Biographies
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- C. Health Literacy Symposium Planning Committee
- D. Accompanying Materials

# I. Introduction

On August 1-2, 2001, the U.S. Department of Education's Division of Adult Education and Literacy (DAEL) convened a symposium entitled "Health Literacy: Implications for Seniors." The symposium was designed to engage health and adult education practitioners in dialogues regarding strategies to help older adults with limited basic skills and their families to communicate more effectively with their health-care providers. Agencies contributing to the symposium include the U.S. Department of Health and Human Services, the National Institute for Literacy, Emory University, the Georgia State Department of Technical and Adult Education, the American Medical Association, the National Center for the Study of Adult Learning and Literacy, National Senior Citizens Education and Research Center, World Education, and the System for Adult Basic Education Support.

This volume summarizes the symposium's presentations and contains relevant accompanying materials. It is organized as follows. **Section II** contains DAEL's letter introducing the symposium, a summary of Ronald Pugsley's opening remarks, and the symposium agenda. **Section III** includes summaries of each presentation, and **Section IV** summarizes a plenary discussion of key issues.

**Appendix A** includes presenters' biographies. **Appendix B** is a complete list of participants that includes contact information to facilitate networking. **Appendix C** lists the members of the committee that helped plan the symposium through a series of conference calls over a number of months. **Appendix D** complements Section III's summaries by including overheads, PowerPoint slides, and other materials that accompanied the presentations made at the symposium.

## II. Background Information

UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF VOCATIONAL AND ADULT EDUCATION

JUL 19 2001

Dear Colleague:

The U.S. Department of Education is sponsoring a health literacy symposium entitled, **Health Literacy: Implications for Seniors** that will be held on August 1 –2 in Washington, DC at the Four Points Sheraton Hotel. I am pleased to invite you to participate in this important symposium. This symposium is designed to engage states and organizations in dialogues to address strategies to help older adults and their families with limited basic skills to communicate more effectively with their health-care providers. Contributing agencies include the U.S. Department of Health and Human Services, the National Institute for Literacy, the Georgia State Department of Technical and Adult Education, the American Medical Association, the National Center for the Study of Adult Learning and Literacy, National Senior Citizens Education and Research Center, World Education, Adult Literacy Media Alliance, and the System for Adult Basic Education Support.

This is a chance to collaborate with health and adult education practitioners about strategies to increase awareness and to discuss approaches to enhance the literacy and communication skills of this population. If you are unable to participate, please send a representative.

Registration information is attached to this letter. If you have any questions about the symposium, please contact Kiki Hunter at (202) 205-9414. We look forward to seeing you soon.

Sincerely,

Ronald S. Pugsley
Director
Division of Adult Education
and Literacy

Enclosure

600 INDEPENDENCE AVE., S.W. WASHINGTON, D.C. 20202

*Our mission is to ensure equal access to education and to promote educational excellence throughout the Nation*

## Symposium Perspectives: Introductory Remarks

*Ronald Pugsley, Director*
*Division of Adult Education and Literacy*
*U.S. Department of Education*

Ronald Pugsley opened the conference by welcoming participants and describing the purposes of the symposium. He also provided a brief summary of how DAEL became interested in the topic of health literacy, and described several of the presentations that would follow during the two days of the symposium. By way of introducing the symposium, Pugsley noted that "today's mantra is 'No Child Left Behind'; the mantra for this symposium is 'No Learner Left Behind.'"

Pugsley emphasized the complex relationship between education and health, and expressed the need for greater discourse among representatives of adult education, public health, medical, research, and other fields in order to advance health literacy to the forefront of the public agenda. He explained that the symposium organizers sought to bring together members from these various fields, in an effort to foster collaboration and share ideas across disciplines, as well as to raise public awareness, with a focus on the needs of older adults.

According to Pugsley, DAEL's original interest in health literacy stemmed largely from research conducted by people such as Ruth Parker, Dave Baker, and Mark Williams, who found a "52 percent increase in the risk of hospitalization in patients with low-level or inadequate literacy." He also cited the recent study by Robert Friedland and Greg O'Neill, which estimated that low health literacy skills cost the U.S. roughly $73 billion per year in otherwise unnecessary health expenditures. Pugsley commented that, from the medical side, Pfizer has been involved with the health literacy issue for several years, as has the American Medical Association's Council on Scientific Affairs. However, he argued that the education community has yet to fully come to grips with the issue, lagging behind the medical community in addressing the needs of individuals with low levels of health literacy.

Pugsley concluded his remarks by challenging adult educators to incorporate health literacy-related lessons into adult education and literacy classes, expressing his hope that the symposium would serve to raise awareness of the need for a strong, multidisciplinary response to pressing health literacy needs.

# Health Literacy: Implications for Seniors[1]

**Four Points Sheraton Hotel**
**1201 K Street, NW**
**Washington, D.C. 2005**

**August 1–2, 2001**

## Agenda

### Wednesday, August 1

**Franklin D**

| | |
|---|---|
| **7:45 a.m. – 8:45 a.m.** | **Continental Breakfast** |
| **8:30 a.m. - 9:00 a.m.** | **Welcome**<br>**Symposium Perspectives**<br>*Ronald Pugsley*<br>*Director, Division of Adult Education and Literacy* |
| **9:00 a.m. -9:30 a.m.** | ***Overview of Health Literacy:*** |

- **Health Literacy 101: Perspectives on Literacy and Health Literacy** This presentation offers perspectives on health literacy and adult education. Except for preventive medicine, the goals of health care tend to be short term, and focus on events (successful treatment). The goals of adult educators tend to be long term and focus on growth and development by increasing student skills. Nonetheless, we have many opportunities to work together to benefit patients and students of all ages. What can we learn from past and present collaborations to move us forward? *Leonard Doak, P.E. and Cecilia Doak, M.PH.*

- **Health Literacy: Advancing the Public Good** This presentation will discuss various research projects as well as highlight opportunities that are currently underway to increase the public awareness of health literacy issues. *Scott Ratzan, M.D.*

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[1] The agenda does not reflect minor timing adjustments that occurred during the symposium.

| | |
|---|---|
| 9:30 a.m. - 10:30 a.m. | **Health Literacy and the Adult Learner: Experiences, Perceptions, Issues** Limited literacy skills have implications for people's ability to access information and care. Without attention to health literacy, the goals, objectives, and strategies in public health and in medicine are compromised. This presentation opens with a video on health literacy, featuring experiences of adult learners. Dr. Rudd discusses the importance of health literacy in the context of health promotion, disease prevention, and health maintenance. The discussion references and draws from the health related experiences of adult learners at home, in the community, at work, and in health care settings. *Rima E. Rudd, Sc.D.* |
| 10:30 a.m. - 10:45 a.m. | **Break** |
| 10:45 a.m. - 11:15 a.m. | **An Overview of the National Assessment of Adult Literacy** The 2002 National Assessment of Adult Literacy (NAAL) will present the first assessment of literacy skills of America's adults in a decade, including adults of all ages. The NAAL will also measure the health literacy skills of adults. Cognitive items included in the assessment represent three domains of health literacy: clinical activities, prevention activities, and navigating the health care system. The NAAL's background questionnaire also has also been expanded to include a new area on health that includes questions relating to health issues and sources of information. *Mark Kutner, Project Director (NAAL)* |
| 11:15 a.m. – 11:30 a.m. | **Healthy People 2010** This will be a discussion of the Healthy People 2010 objectives on health literacy. There will also be a description of the Health Literacy Component of the 2002 National Assessment of Adult Literacy (NAAL) and its relevance for the objective and health communication and health literacy practice. *Cynthia Baur, Ph.D.; Moderator – Julia Shepherd, Deputy Director, DAEL* |
| 11:30 a.m. - 12:30 p.m. | ***Panel Discussion:*** **Health Literacy and Adult Education Practices and Older Persons' Perceptions** State adult education leaders will discuss health literacy activities and promising practices in their respective states. *Kim Lee, GA; Yvonne Thayer, VA; Bob Bickerton, MA; and Cheryl Keenan, PA; Moderator – Glenn Young, Learning Disabilities Specialist, DAEL* |

**Franklin C**

**12:30 p.m. – 1:30 p.m.** **Lunch**

**Franklin D**

**1:30 p.m. – 2:00 p.m.** **Responding to the Need**

This presentation will discuss how to assess health literacy skills & establish and operate health literacy programs. It will also highlight practices implemented by clinics, hospitals and community health centers to address the needs of people with low health literacy. *Kristen Kiefer, M.P.P.; Moderator – Carroll Towey, Senior Advisor, DAEL*

**2:00 p.m. – 2:15 p.m.** **Break**

**2:15 p.m. – 4:30 p.m.** ***Breakout sessions:***

**Franklin A**

- **Reducing Health System Barriers for Patients with Limited Literacy**
  This session will be an examination of the barriers patients with low literacy face in obtaining needed health care services and in one-on-one encounters with health care professionals. *Joanne Schwartzberg,* M.D.

- **Age, Literacy and Learning**
  This session will present data on changes in literacy with age and synthesize related research on cognitive change among the older population. Implications of these findings for learning interventions for those with low literacy skills will be discussed. *Steve Reder, Ph.D. and David Morgan, Ph.D.*

  *Moderator – Cindy Towsner, Education Program Specialist, DAEL*

**Franklin D**

- **Working Together to Improve Health Communication with Older Adults** Learn why medical information is often difficult to understand and increase your awareness about common communication barriers with older adults. Team up with your colleagues to explore practical ways that health professionals and literacy specialists can work together to improve understanding. *Helen Osborne, M.Ed. OTR/L*

- **Do You Want to go to Jail for Cardiac Arrest? Health Literacy and Immigrants New to English**
  This session will discuss barriers encountered by immigrants who are new to English and/or new to the United States. Promising practices in addressing these issues within an adult literacy/ESOL program will be demonstrated. Information in this session is based on a project with elders from Eastern Europe, the Philippines, and Mainland China. *Heide Wrigley, Ph.D.*

  *Moderator – Will Saunders, Education Program Specialist, DAEL*

**4:30 p.m.** **Adjourn**

## Thursday, August 2

### Franklin D

| | |
|---|---|
| **7:45 a.m. – 8:30 a.m.** | **Continental Breakfast** |
| **8:30 a.m. – 10:00 a.m.** | **LINCS and The Health & Literacy Special Collection**<br>Learn about LINCS, NIFL's Web-based information system for adult literacy practitioners, and the Health & Literacy Special Collection, a more specialized collection of health resources designed for teaching health to adults with limited literacy skills. These sites lead to health literacy resources on the Web, including background information on the links between health and literacy, curricula and teaching activities, and low-literacy health education materials on a variety of health topics. Resources that can help practitioners from the fields of health and literacy provide health information to older adults with limited literacy skills will be highlighted. *Carolyn Staley, National Institute for Literacy; William Hawk, National Institute for Literacy; Sabrina Kurtz-Rossi, World Education; Julie McKinney, World Education; Moderator – Kiawanta Hunter, Education Program Specialist, DAEL* |
| **10:00 a.m. - 10:15 a.m.** | **Break** |
| **10:15 a.m. - 11:15 a.m.** | **A View from the Field: A Health and Literacy Collaboration** The Health Education Center (HEC), a non profit affiliate of Highmark Blue Cross/Blue Shield, in collaboration with the Adult Literacy Media Alliance, producers of TV411, provide a range of community health/literacy services to residents of Allegheny County, Pennsylvania. The program provides mostly senior citizens with the skills they need to communicate basic health needs and to perform necessary health tasks in everyday life. This presentation will share information about how this collaboration came into being and delve into what this community health service and multimedia literacy program do jointly to address the basic skills needs of adults. *Jewel Mosley, M.PH. and Dynishal Gross; Moderator – Joyce Campbell, Acting Branch Chief, Program Improvement, DAEL* |
| **11:15 – 12:00** | **Final Thoughts**<br>*Ronald Pugsley, Director, DAEL* |
| **12:00 p.m.** | **Adjourn** |

# III. Summary of Presentations

This section contains summaries of each of the presentations. Each summary contains an overview of the presentation, followed by a summary of key issues covered (generally in the order they were presented). These concise summaries are not meant to substitute for the presentations, which ranged from 30 to 90 minutes, but provide a general description along with key points that each presenter emphasized. Appendix D contains materials that accompanied the presentations, including overhead notes, PowerPoint slides, fact sheets, and other information.

## Health Literacy 101: Perspectives on Literacy and Health Literacy

*Leonard Doak, President*
*Cecilia Doak, Director of Education*
*Patient Learning Association, Inc.*

Leonard and Cecilia Doak presented an overview of key issues related to health literacy, offering a combined perspective from the fields of literacy and public health, which reflects their respective professional backgrounds. Their talk emphasized that the health and education fields address issues using different philosophies, with health providers typically focusing on shorter-term outcomes (successful treatment) compared with educators' emphasis on long-term outcomes (learning). However, the Doaks insisted that the fields share common ground and ample opportunities exist for collaboration across disciplinary boundaries. They challenged the audience to use the lessons of the symposium as catalysts for increased partnership in addressing the issue of health literacy.

Below are a number of key points from the Doaks' presentation:

- **Health care providers' understanding of health literacy**
  The health community often holds misconceptions about how language affects interaction with patients, since medical professionals are not trained as teachers. Rather, they are trained to give explicit instructions and expect these instructions will be carried out accurately. Put bluntly, according to the Doaks, "literacy is not understood in the health community." For instance, an orthopedic surgeon writes out instructions for treatment without guidance from educators who have a grasp of the patient's ability to comprehend the instructions.

- **Structure of the health care system**
  The nature of the health care system, which features short and irregular visits with patients, often fails to deal with the crucial issue of patient understanding. This is in part due to time constraints, especially since today's HMOs often limit physicians to 12 minutes or less of interaction per patient. These time constraints limit the ability

of medical professionals to elicit responses that would inform them regarding patients' understanding of instructions. For example, a physician usually does not ask a patient to describe how he will take a medication, or how he will change a bandage. Furthermore, patients may encounter difficulties in handling current methods used to communicate with them. For example, individuals with literacy difficulties often check off the "no" boxes on medical history questionnaires because they do not understand terms and are afraid to ask for clarification.

- **Health care providers' role in overcoming health literacy barriers**
  Health care providers can help further patients' health literacy by explaining access to the medical system; working to obtain a thorough medical history for each patient (not simply relying on complicated questionnaires); and carefully explaining diagnoses, treatment options, and medication regimens. Furthermore, health care providers must communicate across disciplines, since the medical field is highly segmented into oncology, cardiology, neurology, and so on, in order to help provide clear and coordinated paths to well-being for patients.

- **Educators' understanding of health literacy**
  Literacy educators typically view health literacy problems as a skill deficit on the part of patients, instead of viewing the issue as a communication deficit involving patients *and* providers. Educators must work with patients and health care workers to build communication skills.

- **Educators' role in overcoming health literacy barriers**
  Educators are trained as teachers, and typically offer training to students over an extended period of time with frequent interaction. Also, students tend to be more likely to admit a lack of understanding to their teacher, while patients rarely are this forthcoming with their physicians. This honest relationship between students and instructors puts educators in a strong position to help address health literacy issues. Educators have the opportunity to further health literacy by explaining access to the health care system and other health literacy topics within the context of adult education and literacy classes. Health literacy can even be incorporated into basic literacy and numeracy exercises, in order to connect with low literacy level students. The subject may even serve to draw new students into adult education and literacy classes who might otherwise not be interested in enrolling.

- **Work being done to foster health literacy**
  Despite the obstacles to overcome, such as a medical field that is highly segmented (the American Cancer Society, American Heart Association, etc. reflect the specialized arenas in which medical professionals work), efforts are underway to address health literacy problems and raise awareness. In fact, a recent Internet search turned up over 15,000 entries on health literacy. Pfizer is working to develop standards for giving directions for taking the medicines they manufacture. The University of Colorado has used trained actors to emulate low-literacy patients for its medical students. Also, many health education projects now involve adult educators.

- **Remaining barriers**
  Although progress is occurring, much work remains to create a health literate nation. A poignant example of this need is that the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) guidelines for food intake represent a NALS Level 5 task, even though WIC is most needed in disadvantaged populations among people who often have lower literacy levels. There is a need for more publications describing model collaborations between the medical and educational fields, as well as more health care materials written at lower reading levels. Research that has been done on functional literacy could be used to help identify the literacy demands of key health care tasks, in order to point out areas that need special attention.

## Health Literacy: Advancing the Public Good

*Scott Ratzan, Editor-in-Chief*
*Journal of Health Communication: International Perspectives*

Scott Ratzan continued the symposium's overview session on health literacy, which the Doaks opened, by providing a broad-ranging examination of the issue. Ratzan spoke about the close connection between health and literacy, and provided a concise definition of the phrase "health literacy." He defined the term as "the capacity of individuals to obtain, interpret, and understand basic health information and services necessary for appropriate health decision-making," and used this definition as a segue into examining the current status of health literacy in the U.S. He also described some of the costs associated with low health literacy and strategies for addressing these concerns. Ratzan's presentation emphasized the importance of health literacy for all people throughout their lives and the need to address shortcomings through a collaborative approach.

Some specific topics and statistics Ratzan discussed include:

- **Health literacy's emergence**
  The concept of health literacy has only recently begun to enter the mainstream. The Office of Health Education, which was established in 1991 at the Centers for Disease Control and Prevention, was the first place to address seriously the issue of health literacy. Today, awareness and understanding of the issue are much greater.

- **Low literacy's impact on health maintenance**
  Estimates show that 90 million people in the U.S. have low or marginal literacy levels, and lower literacy levels are associated with reduced preventive health care practices. For example, 25 percent of women do not know the difference between a pap smear and a mammogram. Forty percent of patients do not know what is meant by the medication instruction "on an empty stomach." Many women do not seek effective pre-natal care, which can result in babies with low birth weights and other problems. In addition, the immunization rate among low literacy groups lags behind. Meanwhile, research has shown that well-educated populations are more likely to lead healthy lifestyles. In a European study, higher education levels were clearly linked with non-smoking behavior. It is reasonable to assume a similar link exists in this country for health concerns such as HIV.

- **Costs of poor health literacy**
  The results of low levels of health literacy include an enormous monetary loss to society (i.e., unnecessary health care expenditures), as well as devastating costs at the individual level. There are numerous documented stories of patients' problems with health literacy, including misuse of suppositories, ingestion of ear drops, and many other vivid and more mundane but equally worrisome examples. More generally, many patients encounter difficulties navigating the health care system, from knowing how to obtain proper treatment to understanding how to follow medication regimens

and read prescription drug labels. Since health literacy-related problems reduce individuals' potential to practice good preventive health behaviors and increase the likelihood of patients' mismanaging treatment for illnesses, patients with low health literacy are at greater risk and society must bear unneeded costs.

- **Patients and professionals as part of the solution**
  People working to improve individuals' health literacy must keep in mind that the goal should be enabling individuals to make decisions affecting their health. Patients need to be helped to understand information such as diagnoses and the purposes of the medications they take, and must develop the ability to weigh risks and make decisions independently. Also, professionals need training to address gaps in their understanding of what health literacy entails. They need help learning how to communicate appropriately with patients and with one another.

- **Three keys to a healthier life**
  In order to maintain their health, individuals should know the answers to three basic questions: "What do we do to keep ourselves well?"; "If we are getting sick, how can we detect and treat these conditions early?"; and "If we are sick, how do we get the best medical care?" Roughly two-thirds of our money is spent in dealing with medical care to cure illness, yet perhaps three-quarters of problems could be addressed simply by better answering the first two questions.

- **Enabling steps toward increased health literacy**
  In order to move toward a health literate U.S., society must first recognize the issue. Researchers must develop baseline measures of health literacy, and people must work to create a "health legend" that provides a common language to help frame health literacy issues. Leaders in various fields must identify key partners who work across boundaries to address health literacy. Since health literacy is a broad issue that presents an opportunity for a "new way" to bring fields together, communication is central to creating needed linkages among fields.

- **Opportunities to raise health literacy**
  Health literacy can be influenced through many channels, including the media, providers, and policy. Means to improve health literacy could include enhanced school and workplace education, community-based projects, professional education and incentives, and other varied strategies. Health literacy needs to be taught widely, since it affects service delivery across the medical community, including child health, family health, reproductive health, mature health, and critical health.

# Health Literacy and the Adult Learner: Experiences, Perceptions, Issues

*Rima Rudd, Professor*
*Department of Health and Social Behavior*
*Harvard University School of Public Health*

Rima Rudd's presentation focused on the effects of low literacy skills on individuals' ability to find out about and gain access to quality health care. She highlighted the importance of addressing health and literacy in conjunction, since the areas overlap and have a major effect on individuals' health. Rudd focused her talk on the obstacles to adult learners as they attempt to navigate the various components of the health care system. The talk's emphasis was the need for more effective methods of communication with patients; Rudd argued that currently "we aren't talking in a way that can be understood." Her presentation included a video entitled "In Plain Language," which is available at http://www.hsph.harvard.edu/healthliteracy/video.html. The video features adults with limited literacy skills discussing their experiences with the health care system, as well as discussions with health care providers and researchers.

Some of the key points and examples from Rudd's presentation are as follows:

- **Demographic and health data**
  Research has documented that as an individual's social position increases, so does his health; likewise, health deteriorates as social position declines. Similarly, death rates for chronic diseases, communicable diseases, and injuries are inversely related to education. Other determinants of health include income, gender, age, race, and occupational hazards.

- **Literacy and health data**
  There are only about a dozen studies that link literacy with health outcomes. While it appears logical that literacy has a major effect on health, more research is needed to show the connection and broaden the scope of health literacy. This research must recognize that literacy plays into an individual's ability to obtain services, since individuals must be able to translate from medical jargon to understandable information. The studies we have indicate a clear conclusion—health providers are not succeeding in communicating with patients. Research has indicated higher hospitalization rates for the low literacy population, and that health documents are consistently written at inappropriately advanced levels.

- **The importance of health literacy**
  Health literacy is one component of functional literacy, as health literacy is required to enable people to seek and obtain effective health care. When accessing health care, individuals must complete forms, provide detailed information, sign consent forms, understand often complex directions, follow medication regimens, and know to ask appropriate questions to clarify information (e.g., without a rich vocabulary, it is difficult to describe symptoms to a physician). Literacy plays into all facets of life,

and the connections between literacy and issues such as health are crucial. For example, applying for food stamps requires adequate literacy skills to complete a 72-page document; health may, in turn, be affected dramatically by the inability to obtain food stamps. The same is true of applying for Medicaid and Medicare, as well as understanding coverage provided by private health insurance plans. Other such indirect connections involving literacy skills are abundant. Thus, simply being able to follow medication directions does not mean one is health literate. Broader abilities, for example being able to form a community association to counter asthma triggers, must also be considered under the umbrella of health literacy.

- **Problems leading to ineffective communication**
  Physicians often work from flawed assumptions of what patients know. For example, people are taught in school to think sequentially and use formal thought processes, and the medical setting is based on this same philosophy. However, people with low literacy skills may not be trained to think in this manner. Even patients with higher literacy levels may lack core knowledge about health and their bodies, as the K-12 school system does not place a significant emphasis on such topics.

- **Recent health literacy research**
  The National Center for the Study of Adult Learning and Literacy (NCSALL) is currently conducting a health literacy study that includes: a literature review; patients' stories; an examination of media's role; issues associated with system navigation; and an assessment of health care documents (including Medicaid forms). The researchers have found that many documents are written at a college or higher grade level. The study pays particular attention to asthma and osteoarthritis, since the former requires a complicated treatment regimen while the latter is much simpler to manage.

- **Costs of low health literacy**
  When patients are unable to communicate effectively with health care providers, the effects are both physical and emotional. Patients may get lost in hospitals, or show up to appointments at the wrong time. They may not be able to follow medication regimens, or decide to abandon treatment altogether. Patients may not voice their questions and concerns, silencing themselves out of shame and fear stemming from a breakdown in communication. This may lead to patients assuming a passive role in interacting with providers, and they may even lose entitlements due to inadequate communication.

- **Special barriers facing seniors**
  Seniors face particular health literacy challenges, as 33 percents of adults at NALS Level 1 are ages 65 or older. Forty-nine percent of this cohort has difficulty with document literacy, a major issue given the structure of the health care system, which involves numerous forms, questionnaires, schedules, directions for care, and medication administration instructions. Older adults also have a greater need for care due to physical changes, such as visual and sensory impairments, that come with age.

- **Connections between fields**
  There are parallels between adult education and health care, and members of these fields must build on each other's strengths. For instance, providers in the fields serve similar populations (e.g., the at-risk, poor and marginalized). They must contend with issues of motivation and engagement, and need to be sure to work to create a dialogue with the students/patients they serve. Indeed, the need for dialogue is crucial, as students/patients must be given a voice; Rudd explained the importance of this need by stating, "silence is the equivalent of an illness."

## An Overview of the National Assessment of Adult Literacy

*Mark Kutner, Project Director*
*National Assessment of Adult Literacy*
*Pelavin Research Center, AIR*

Mark Kutner spoke about the upcoming 2002 National Assessment of Adult Literacy (NAAL), which will include health literacy measures for the first time. NAAL represents the first literacy study of its magnitude in the U.S. since the 1992 National Adult Literacy Survey (NALS), NAAL's predecessor. Kutner discussed how the study is designed, the items it will measure, and the types of data it will provide. He focused on a general discussion of NAAL, leaving the details of the study's new health literacy component for Cynthia Baur to cover.

Listed below are key points Kutner made during his presentation:

- **Overview of NAAL**
  The basic aim of NAAL is to assess people's ability to use the printed word to achieve their goals. NAAL measures this ability by simulating focused reading tasks that adults would likely engage in to find specific information. NAAL utilizes written materials that adults come across on a day-to-day basis, such as advertisements, newspapers, prescriptions, and utility bills. It is not a reading test per se; rather, NAAL assesses how well individuals can glean specific information from documents. NAAL tests three dimensions of literacy: prose literacy, which includes newspapers, pamphlets, and fiction; document literacy, which includes tables, application forms, and schedules; and quantitative literacy, which includes numbers embedded in text such as checkbooks.

- **Sampling methodology**
  NAAL involves a nationally representative sample of individuals aged 16 and older. The data collection includes a national sample of 13,000 adults and a 1,000 person state-level sample for each participating state. Researchers will over sample African-Americans and Hispanics in order to ensure statistically significant findings. NAAL has no upper age limit for survey respondents at the national or state levels, unlike in 1992 when state-level surveys had an age limit of 65. According to Kutner, this change makes particular sense because the American population is aging. Currently, 21 percent of Americans are 55 years old or older, including 12 percent who are 65 or older.

- **Contents of the survey**
  The study will use seven blocks of questions from the 1992 survey and seven new blocks, which will include health literacy questions. The tests are not given in full to each respondent, so the survey provides useful data for the broader population, not for the individuals who take the survey. Tests will be administered using Computer Assisted Personal Interviewing (CAPI), in order to screen for inconsistent answers. Each assessment is organized into approximately 35 minutes of background

information, including health questions related to areas such as health insurance, general health status, and preventive health activities; 10 minutes of easier "core" items; and 45 minutes of cognitive assessment. These times are estimates, since respondents can take as much time as necessary throughout the assessment.

- **Accessibility to populations with limited English proficiency**
  The background questionnaire can be given in Spanish, as can instructions for the core cognitive items. However, the actual test questions and documents are in English, since the survey measures English literacy; researchers will report separately on the number of people who did not take the test due to a language barrier (as opposed to a literacy barrier). In addition, there is a Supplemental Adult Literacy Assessment, which will be given to the likely 10 percent of respondents who perform poorly on the core items (may be non-English speakers or individuals with especially low levels of literacy). It includes a series of items, such as pill bottles and Coke cans, about which interviewers asks questions to assess respondents' literacy skills.

- **Reporting findings**
  Results from the 14 cognitive health literacy items in the survey (two items in each new block) will be reported using a health literacy index score, which will include data for subgroups (race, gender, income, etc.). Researchers will examine the relationship between health literacy and knowledge of health topics based on the background health information provided by respondents.

# Healthy People 2010

*Cynthia Baur, Senior Policy Advisor*
*Office of Disease Prevention and Health Promotion*
*U.S. Department of Health and Human Services*

Cynthia Baur followed Mark Kutner's NAAL presentation with a brief talk on the health literacy component of the Healthy People 2010 initiative. Baur also built on Kutner's talk with a discussion of the Health Literacy Component of NAAL. Her comments focused on the relationship between Healthy People 2010 and NAAL, and the objective of making health literacy a national issue. Baur views both Healthy People 2010 and NAAL as crucial in building toward a more health literate populace by designing materials at appropriate literacy levels and training individuals to communicate clearly. By improving the public's health literacy, health disparities among demographic subgroups can be reduced and society's overall health can improve.

Baur's comments included the key points listed below:

- **Overview of Healthy People 2010**
  Healthy People 2010 includes two major goals: to increase the quality and years of healthy life people have and to eliminate health disparities among different demographic groups. In order to achieve these goals, Healthy People 2010 contains 28 focus areas and 467 specific objectives, which can be evaluated with baselines, targets, and population data.

- **How health literacy relates**
  Baur leads Chapter 11 of the Healthy People 2010 project, the Health Communication focus area. This chapter contains six objectives: (1) Internet access, in order to raise access to 80 percent of the population; (2) health literacy, which will require additional measures to complement NAAL, since Healthy People 2010 must measure results at the end of the decade (not in 2012, when the next NAAL is scheduled); (3) research and evaluation of health communication programs; (4) quality of health web sites; (5) Centers for Excellence and; (6) assessment of health care providers' communication skills. A problem with addressing these objectives is they are not all measurable given current data availability. Objectives (2) through (6) are still at least partly in the "developmental" stage of measurement, meaning there is a need to develop additional data sources.

- **Overview of NAAL's health literacy focus**
  With the Health Literacy Component of NAAL, researchers want to evaluate how well people can locate and utilize health information and services. These results will be reported through a health literacy index score that includes data for subgroups based on demographic characteristics such as race, income, and geography.

- **Health Literacy Component details**
  There are three domains, or clusters, of health literacy information people frequently encounter. The clinical domain includes physician-patient interactions, filling out forms, and reading printouts of health data. The prevention domain includes, for example, the decision to get an influenza vaccination before the flu season. The navigation domain relates to the ability to navigate the health care system; for example, understanding co-pays and deductibles in health insurance plans. Ability within the domains will be tested using actual health care materials, although it has been surprisingly difficult to find materials that researchers can agree are useful and representative. One problem is that so much health material is at such a high literacy level that it can not possibly provide useful survey information.

# Health Literacy and Adult Education Practices and Older Persons' Perceptions: State Directors' Panel

*Bob Bickerton, State Director of Adult Education*
*Massachusetts Department of Education*

*Cheryl Keenan, State Director of Adult Education*
*Pennsylvania Department of Education*

*Kim Lee, Director of Assessment, Evaluation, and GED*
*Georgia Department of Technical and Adult Education*

*Yvonne Thayer, State Director of Adult Education*
*Virginia Department of Education*

The state adult education directors on this panel took turns sharing vignettes of the health literacy initiatives underway in their home states. The panel discussion aimed to add to the broad background presentations that opened the symposium by bringing attention to the state and local levels. Panel members shared their experiences in becoming involved with the health literacy issue and offered examples of promising practices and ideas for the audience to consider.

**Bob Bickerton** discussed lessons from his work in Massachusetts:

- **Health literacy's emergence in Massachusetts**
  In the last seven years, Bickerton's office has put roughly $4 million into education and health collaborations through a variety of projects. This effort began in earnest in 1994, when a state tax on tobacco went to fund projects relating to smoking cessation and prevention programs, including pilot adult education programs.

- **Strategies for teaching health literacy**
  Life skills-related activities should be incorporated into literacy instruction. Learning must be placed in context, or it is often a waste of adult learners' time. Health literacy is an area that can help fit education into context, since adult learners must deal with the health care system on a frequent basis. Health material can be integrated into numeracy, reading, and writing exercises in adult education and literacy curricula.

- **Lessons for building health literacy programs**
  Key ingredients for creating successful pilot projects related to health include: creating state leadership; having liaison staff at the local level; building mutual partnerships, such as those in which adult education programs work with hospitals to translate medical information into clear language and health workers make presentations to adult education classes; increasing participatory education, where students help to develop curricular materials and determine topics to study; and utilizing family literacy, where literacy takes place in a family context that can present an environment for discussing health issues.

**Cheryl Keenan** spoke about Pennsylvania and shared health literacy strategies:

- **Health literacy's emergence in Pennsylvania**
  Pennsylvania is relatively new to addressing the health literacy issue, in comparison with the states represented by other members of the panel. Furthermore, local areas in Pennsylvania, and elsewhere, are often ahead of states in addressing health literacy. Pennsylvania and other states must work to recognize these "pockets of excellence," and should work mainly to share best practices and set some uniformity in standards.

- **Current efforts**
  The Interagency Coordinating Committee (ICC), which was established in 1996 and began in earnest in 1997, is targeted at adult basic education and has focused primarily on workforce-related issues. The ICC's mission involves coordinating to ensure that literacy is addressed by all state agencies and that literacy is not viewed as simply a reading program. ICC's health literacy focus is on improving outcomes for patients, with a particular emphasis on populations such as the elderly, low-literacy learners, people in the workplace, and minorities. The ICC recently added the state's Physician General and Secretary of Aging, which should boost the prominence of health literacy.

- **Lessons for building health literacy programs**
  There are several lessons to glean from Pennsylvania's experience working to address health literacy. It is key to build upon existing collaborations with some visibility (e.g., utilizing the ICC) rather than starting from scratch. Leaders should work to connect health literacy with the mission of all possible partners. In Pennsylvania, this occurred by linking with Healthy People 2010, workers' compensation and other workplace groups, as well as the first lady's breast cancer initiative. Groups should connect with each discipline to show how it can play a role and how it can benefit. In addition, leaders should be realistic about what can be accomplished; things do not always go as planned at first. Finally, all partners should work persistently to bring policy into practice, understanding that local level change does not happen overnight.

**Kim Lee** provided an overview of health literacy efforts in Georgia:

- **Health literacy's emergence in Georgia**
  The spark for Georgia's work to address health literacy was a National Institute for Literacy (NIFL) item on the issue that caught the attention of the state director for adult education, Jean Devard-Kemp. Discussions regarding health literacy began about 18 months ago.

- **Current efforts**
  Currently, interested parties in Georgia come together through an advisory group that Lee's agency set up to address health literacy. The group includes representatives from university programs in public health and medicine, pharmaceutical companies, the private practice medical community, the AARP, medical and public health associations, and government agencies. Thus far, nobody has turned down an

invitation to join this advisory committee. Also, the Office of Adult Literacy organizes the Teacher's Academy, a yearly training event; in 2001, the focus was the state's Health Literacy Initiative. Over 160 full-time adult education teachers convened to learn from prominent health care professionals. The training covered issues such as AIDS, diabetes, mental health, oral health, and heart disease, in order to help teachers create a curriculum that integrates health-related issues into courses. In addition, Georgia has hired a new staff member to lead their health literacy efforts.

- **Upcoming efforts**
  Georgia has developed a health literacy curriculum to guide instructors. Beginning in September, the state will administer health literacy classes to be taught by part-time instructors at 13 sites across the state, including hospitals, churches, community centers, and other non-traditional locations. This will mark the first time separate health literacy classes have been offered in the state.

**Yvonne Thayer** spoke about health literacy, focusing on the ESL population:

- **Virginia's health literacy focus**
  Virginia has a large ESL population, which includes a range of people, from highly educated individuals to those who are non-literate in their native language. In addition, many areas of the state have ESL waiting lists. To address these pressing needs, Virginia has focused its health literacy efforts on the ESL segment of the adult learner population. The state is addressing health literacy primarily through an English language and civics program funded by the federal government. This effort got off the ground because a physician from the AMA talked the program into including health literacy in the grant proposals.

- **Specifics of the effort**
  All ten health literacy projects are technologically oriented, allowing instructional materials and resources to be shared electronically. Video is used as a primary teaching tool, and is enabling the state to work to develop virtual tours of places like community hospitals, in order to familiarize learners with the medical system. These virtual tours can include visual depictions of the actual hospital in a particular community, with voice-overs and labels helping to identify directions, equipment, and other potential sources of confusion. There is a central repository for all of the course content that has been developed, so programs do not have to duplicate efforts (three of the programs work on curriculum development). Thayer noted that a central repository would be useful on the national level for similar reasons.

- **Partnering with the health field**
  Each of the ten projects involves a health partner, such as the American Cancer Society, Red Cross, and local hospitals. The partners help design and deliver instruction on topics such as how to access medical care and how to use the 9-1-1 emergency system. In general, the health component of the projects aims to prevent illness, enable individuals to obtain proper treatment for illness, and facilitate navigation of the health care system.

## Responding to the Need

*Kristen Kiefer, Research Associate*
*Georgetown University Center on an Aging Society*

Kristen Kiefer's presentation described a project she conducted through the Center on an Aging Society, with support from the Center for Medicare Education. Among other activities, such as providing background information defining health literacy as an issue, the project report examined initiatives working on developing health literacy materials, in order to provide insight into the sorts of activities underway across the country. Kiefer cautioned that the findings from her report are not "best practices," since there is little research examining the programs' effectiveness, but the seven programs highlighted in the study contain useful ideas for designing health literacy initiatives.

Kiefer discussed some findings and examples from her report:

- **Screening for literacy problems in the health setting**
  There are two ways to identify patients who might have literacy difficulties. Formal means include tests such as the Rapid Evaluation of Adult Literacy in Medicine (REALM), which takes about five minutes to complete. REALM is a list of 60 questions, which test a patient's ability to pronounce certain words. It aims to determine patient learning needs, so that treatment regimens, discussions with physicians, and other activities can be targeted to each patient. Concerns with REALM include the possibility of intimidating patients (perhaps even scaring them away). Informal assessments include talking with persons to see what learning style they have; one example observed was a pharmacist who relies on a soda can as a simple tool to assess individuals' literacy level.

- **Helping individuals with literacy barriers through one-on-one counseling**
  There are several ways to assist people with low literacy skills, including one-on-one counseling, group assistance, visual aids, and training programs. Examples of one-on-one counseling include the Purdue pharmacy program, where students work one-on-one with patients with chronic illnesses, in order to check for medication compliance. Patients participating in this program had higher rates of compliance and gained confidence speaking with medical professionals. Another program, in Brownsville, Texas, makes use of volunteer "promotoras," who provide close guidance to people in the community. The promotoras help people sign up for Medicaid, make door-to-door educational visits, and accompany patients to physicians' appointments, among other activities. Telephone hotlines are a more common example of one-on-one assistance.

- **Group assistance**
  Group assistance is generally less intensive, in that it is not a one-on-one experience; however, it can be an effective means of teaching health literacy. A group assistance program exists at El Paso Community College, where adult learners help drive the

health literacy program by guiding instructors in the choice of topics to cover. The program has made field trips to places like the local Medicaid office, and has invited numerous guest speakers to address the class on issues students care about.

- **Visual aids**
  Visual aids, such as pictographs for managing particular conditions, can also help bridge literacy gaps and reinforce written and verbal instructions. Johns Hopkins has developed pictographs to complement oral instruction. A physician can give a patient both verbal instructions and pictographs, and then ask the patient to repeat the instructions. Other examples of visual aids include videotapes, color coding schemes, and easy-to-remember symbols.

- **Training programs**
  Training programs include efforts like the ongoing project at Purdue's pharmacy school, as well as brown bag lunches and other programs where staff members learn skills to meet individuals' health literacy needs.

- **Assessing health literacy programs**
  There have not been formal assessments of the health literacy programs Kiefer examined. Instead, subjective and informal evaluations have been used to measure the success of these programs. For instance, recall rates have sometimes been used to measure program effectiveness. Further work is needed to evaluate health literacy programs' quality.

- **Creating successful health literacy programs**
  There are several common barriers to establishing health literacy programs. Typical barriers to overcome include locating financing for the program, promoting community support, and sustaining the program over the long term. Possible solutions to the barriers listed above include: seeking funding from various sources (Pfizer, government grants, etc.); building on other successful programs (in El Paso, the program began as a grant for women's health); including a feedback loop that seeks adult learners' preferences on how they like to learn; building community support by establishing trust (e.g., the promotoras in Brownsville); seeking to build collaboration between health and education organizations; and demonstrating program strengths and weaknesses with assessments, in order to help sustain support.

## Reducing Health System Barriers for Patients with Limited Literacy

*Joanne Schwartzberg, Director of Aging and Community Health*
*American Medical Association*

Joanne Schwartzberg focused her talk on barriers facing patients with low levels of literacy who attempt to access the health care system. She spoke about changes in the health care system over the years, in relation to their effect on service delivery, and addressed approaches to overcome barriers to system accessibility for low literacy patients. Schwartzberg also presented a large amount of information documenting the nature and extent of the health literacy problem, and illustrating why the issue is often ignored. As part of her presentation, Schwartzberg showed a video entitled "Low Health Literacy: You Can't Tell By Looking," which featured interviews with patients with low literacy. The video contains examples of patients who are unable to understand drug labels, follow medication regimens, and understand the physician's instructions. The video is available from the AMA as part of an introductory health literacy kit, which is described in detail in a fact sheet included in Appendix D.

Schwartzberg spoke about the issues below:

- **Changes to the health care system**
  The health care system has changed dramatically over the last few decades. There has been a proliferation of prescription drugs, from about 650 just 30 years ago to over 10,000 today, which has vastly increased the complexity of care for both providers and patients. At the same time, the amount of time physicians spend with patients has decreased (HMOs set time limits on physician's visits). The length of hospital stays has also decreased over the years. Treatment of new onset diabetes used to entail a three-week hospital stay and two hours a day of diabetic education classes. Today, the education process is handled on an outpatient basis with not more than three hours of diabetic education classes. In short, the health care system has become more complex, yet patients typically receive less personal attention in their interactions with the system. Or, as Schwartzberg put it, "life gets more complicated; we get less education."

- **The literacy barrier**
  NALS Level 1 and Level 2 learners face special barriers in managing their health care needs. Having difficulty with literacy may: make following medication regimens more difficult; make it difficult to understand pill bottles; and create problems understanding appointment slips, information forms, insurance applications, and other health documents.

- **Research findings**
  Recent studies have found that patients frequently have inadequate functional health literacy, including difficulty handling health documents and following medication regimens and treatment plans. Patients with low literacy are also more likely to be hospitalized. Longer hospital stays and other factors contribute to the estimated $73

billion annual cost of poor health literacy. Another study used the Test of Functional Health Literacy in Adults (TOFHLA) and found that health literacy needs increase significantly with age. It remains unclear if this is due to lower school completion rates, declining mental abilities, or a combination of these and other factors.

- **Concealing health literacy difficulties**
  Although low health literacy is a major problem, it remains an undervalued issue. Patients sometimes do not recognize their literacy troubles or may be ashamed and hide their difficulties. They may be hesitant to have their reading ability measured or recorded in medical records due to embarrassment. Moreover, clinicians often do not ask about literacy and are unaware of their patients' problems. They may be nervous about broaching the topic, unsure how to respond if a patient does have a problem, unaware of the magnitude of the problem, or unwilling to deal with it.

- **Literacy myths**
  Many individuals with low literacy may have their difficulties go unnoticed in the health care system because they do not fit stereotypes. In reality, among NALS Level 1 readers, 75 percent were born in the U.S., 50 percent are white, 40 percent hold a full- or part-time job, and 25 percent finished high school. The figures contradict some common misconceptions about individuals with low literacy levels.

- **Physicians' opinion of the problem**
  The AMA has been collecting information about what physicians perceive as barriers to effective communication with patients. Findings indicate many perceived problem areas in office encounters; 87 percent of responding physicians report patients have problems completing medical history forms and an equal number say patients struggle to understand consent forms. Also, eighty-two percent of responding physicians say patients have difficulty in providing insurance information; fifty-seven percent say following signs and directions to their office is difficult for patients; and forty-seven percent indicate that patients have trouble interacting with office staff.

- **Techniques employed by physicians**
  The AMA has also collected information on techniques physicians use in dealing with patients; this study found that many physicians are not using good communication practices even when they believe these practices to be effective. For example, only 31 percent of respondents have reported that they often ask patients to repeat information back to them (the "teach back" technique), although 56 percent believe this is an effective practice. Ironically, 56 percent of respondents said they often hand out printed materials to patients, yet only 31 percent believe it is an effective practice.

# Age, Literacy and Learning

*Stephen Reder, Professor*
*David Morgan, Professor*
*Institute on Aging*
*School of Community Health, Portland State University*

Stephen Reder and David Morgan presented background information and research findings on changes in literacy and cognitive functioning associated with age. Their talk explored national data that demonstrate a sharp decline in literacy proficiency that begins around age 45. Reder and Morgan examined various other influences on literacy, in order to separate age from other factors affecting literacy. They assert that the decline in literacy proficiency with age remains significant even when these other confounding variables are removed from the equation. Reder and Morgan called for more research to confirm the age-based decline in literacy proficiency, and stated that the age-based decline mirrors studies that show a decline in cognitive capacity with age. This research leads to the conclusion that older adults are experiencing a loss of cognitive capacity and reduced literacy proficiency at the same time that they are beginning to require more health care. If research demonstrates that this intersection of reduced abilities and increased needs exists in practice, then it raises a variety of questions with which health care practitioners and adult educators must contend.

**Reder** opened the presentation by discussing the association between aging and literacy proficiency:

- **Everyone ages**
  The elderly are a unique population, since all people eventually belong to the category. Thus, age's influence on literacy and cognitive functioning must be examined to understand how health literacy affects the elderly population.

- **Clarifying the definition of health literacy**
  Literacy and health literacy are related but not identical concepts. Functional literacy influences health and is a capability that can be measured on a continuous scale. Health literacy is a broader concept than functional literacy, since it involves a number of factors that may not be directly related to literacy (e.g., one's ability to stick to a schedule).

- **Age and NALS scores**
  Examination of literacy level by age using a 500-point proficiency scale based on NALS scores, indicates an increase in proficiency from years 16 to 44 followed by a clear decline thereafter. Average literacy levels drop from a high of about 290 points to a low around 220 points at the end of the curve. However, this dramatic downward curve does not take into account educational attainment, income, physical disabilities, and other factors that may confound the data.

- **Confounding factors**
  The curve flattens slightly when adjusted for educational attainment, yet the drop remains. Moreover, the curve still exists after accounting for labor force status (even in the case of full-time professionals with four-year degrees) and other factors such as the presence of disabilities. In fact, the substantial decline in literacy proficiency with age appears to cut across social, economic, and educational divides. Nonetheless, despite the strong trends, the data remain difficult to interpret because they are cross-sectional, not longitudinal. The 2002 NAAL should help meet some research needs, such as providing a comparative framework, but more data (e.g., a true longitudinal study) is still needed to confirm and explain the trends.

**Morgan** followed Reder's comments with a discussion of the link between aging and cognitive ability, and some ideas on how cognitive research can add to the dialogue regarding information acquisition:

- **Types of intelligence**
  Cognitive loss discussions require the definition of two key terms. "Crystallized intelligence" refers to familiar procedures, such as vocabulary. "Fluid intelligence" refers to unfamiliar procedures, such as processing speed. Learning differs based on whether it requires fluid or crystallized intelligence. For instance, according to lab research, vocabulary (crystallized) does not decline much with age, while processing speed (fluid) drops dramatically.

- **Barriers to learning**
  Learning difficulties can be accounted for based on a variety of factors. For instance, there are limits on the acquisition of information due to sensory loss and environmental distractions. Limits on information processing relate to the presence of complex, unfamiliar, and excessive information, while the existence of distracting or irrelevant information and time pressure also creates barriers. In addition, limits on the use of information one processes are associated with the need for complex and unfamiliar tasks. In general, the more complicated and unfamiliar information is, and the more distractions present, the more difficult it is to learn.

- **Overcoming barriers to learning**
  Methods exist for improving individuals' ability to learn. Successful acquisition of information can be enhanced by providing a better environment for relevant information with fewer distractions, and through efforts to write things down and use other strategies to improve individuals' ability to retain information. Information processing can be improved by simplifying complex information and clarifying it by using conceptual frameworks, such as breaking information into manageable chunks, as well as by minimizing distractions and providing ample time. Successful use of information also can be enhanced through simplifying complex tasks and using conceptual frameworks, as well as by linking new types of tasks with familiar ones.

- **Future research**
  Reder and Morgan plan to pursue further research related to age, literacy, and cognitive capacity. Areas to address include whether differences shown in NALS and measures of cognitive capacity cross-validate (i.e., are the similar curves related or simply due to coincidence?). Also, they will investigate whether NALS findings and lab research predict real world limitations for older adults. If so, strategies such as the techniques listed above must be developed to help older people improve functioning. If NALS and other research findings relate to the real world, then the results may help identify promising strategies for coping, as well as barriers.

# Working Together to Improve Health Communication with Older Adults

*Helen Osborne, President*
*Health Literacy Consulting*

Helen Osborne's presentation aimed to convey patients' difficulties in understanding medical information, and to increase participants' awareness of common communication barriers with older adults and the ESL population. Osborne shared some of her experiences working as an occupational therapist and health literacy consultant, and offered specific strategies for improving health communication with older adults. She spent roughly half of the session sharing her thoughts with the whole group, while the remaining time was devoted to small group discussions regarding relevant case studies. The three case studies covered scenarios focusing on the prevention of accidental falls in a hospital, dealing with an elderly patient's English language barrier, and raising general awareness about health literacy (see Appendix D for the case study sheets).

Osborne raised a variety of issues, including those listed below:

- **Helping patients understand**
  Patients appreciate efforts to make materials easier to understand, which may require customizing content to meet learner needs. For instance, Osborne reformatted the standardized occupational therapy assessment into a series of questions, and with the help of ESL students was able to translate the questions into multiple languages. In one case, she was able to hand a Chinese patient an assessment in his own language, which marked the first time he had been able to understand a document since entering the hospital.

- **Delivering services to ESL and low-literacy populations**
  There are many additional challenges in providing health care to non-literate or ESL patients. Some challenges include cultural differences that create barriers in explaining certain concepts; potential language-related pitfalls in the way statements are phrased ("when you make mistakes with medicine" might be interpreted as an attack rather than a gentle reminder); and difficulty building trust. Strategies to overcome these barriers include: focusing on truly working *with* patients, rather than for them; treating patients with a high level of respect, a mantra of the adult literacy field; and asking patients why they are seeking care, rather than making assumptions, as is common in the health field.

- **Health literacy as a specific barrier**
  Health literacy is often a special barrier to direct care situations, when immediate decisions must be made for the safety and well-being of the patient. There are short-term and long-term health literacy issues to deal with in providing health care. In the short term, there is a need to remedy the illness. In the long term, it is important for providers to build patients' language skills, establish a trusting relationship, and

increase patients' ability to self-advocate and ask questions when they need clarification.

- **Raising awareness**
  There are many ways to get the message out about the need for health literacy. Examples include health fairs, health screenings, listservs, reports and studies, PTA meetings, and adult education courses.

# Do You Want to go to Jail for Cardiac Arrest? Health Literacy and Immigrants New to English

*Heide Wrigley, Senior Research Associate*
*Aguirre International*

Heide Wrigley began her presentation by explaining its title. She stated that ESL speakers might understand the word "arrest" but have no idea what "cardiac" means, thus creating the potential for a serious misunderstanding. In order to underscore the difficulties inherent in communicating with the ESL population, she cited an example of a Hmong interpreter who thought that a public health advisory against eating seafood, including mussels, referred to cannibalism. Wrigley provided numerous other examples of misunderstandings that can occur due to language and cultural barriers—many of which might not be obvious even to a provider working hard to be sensitive to health literacy needs—and offered promising practices for overcoming these barriers.

Some of Wrigley's key points and pertinent examples include the following:

- **Broadening the scope of health literacy**
  Health literacy involves more than reading and writing; it includes oral communication and other more subtle forms of communication (cultural, non-verbal, etc.). These other forms of communication can create unforeseen stumbling blocks.

- **Cultural barriers**
  Cultural misunderstandings can be a major barrier. For example, in one case, Hmong people were nervous about providing blood samples for medical testing, since they associate blood with a person's soul. Further complicating matters, through a series of misinterpretations, a rumor spread among the Hmong community that their children's blood was being stolen to fill a blood bank. Similarly, in Mexico, many people believe that taking a shower when you are hot will make you catch a cold, which created a barrier to a public health campaign aimed at counteracting pesticide exposure among migrant farmhands. Visual and other non-verbal communication cues also vary by culture. For example, in Chinese and Vietnamese cultures, nodding indicates politely acknowledging someone but does not indicate understanding what the person is saying. Similarly, tone of voice often carries more meaning than grammar, which is why Filipino nurses are sometimes perceived as rude by patients from other cultures.

- **The impact of shame**
  Even when efforts are made to communicate clearly, and there are no indications that the patient has concerns, problems may exist. Individuals are often embarrassed to admit that they do not understand, and become even more embarrassed if they have to ask the same question again and again yet still do not understand. Thus, it is not uncommon for a patient who does not understand to choose silence over embarrassment.

- **Child translators**
  In immigrant families, children often become translators, which can have serious drawbacks. The children may be unable to adequately translate complex medical concepts, but even perfect translation may have unintended consequences. For instance, having children in the crucial translator role can change the power balance in a family and create tension. Also, having children in the translator role can create privacy issues and may make patients and their families feel uncomfortable.

- **Patients' legal rights**
  Medicaid coverage can be denied for up to six years for immigrants, depending on the state, which creates a system where legal residents in the U.S. may be excluded from basic medical care. Also, ESL speakers have a legal right to translators' services, but if no translator is available, then the right may be ignored. This is a particularly difficult issue to contend with at hospitals during late hours when translators are less accessible. Moreover, in order to receive translation services, ESL patients are often better off telling people they speak no English because their request for a translator will likely be brushed off if they admit to speaking English, even if they speak it poorly.

- **Strategies to improve communication**
  There are a number of promising practices for working to improve communication with ESL speakers. For example, ESL workers or other service providers can conduct health literacy inventories that help patients figure out their knowledge strengths and gaps (e.g., a patient may be strong when it comes to following medication directions but need help in asking questions of the physician during the office visit). Walk-arounds are a way of helping patients become familiar with the health care setting by guiding them through the process of accessing care. Community mapping can help identify where health care facilities are located in each neighborhood, creating a resource to which patients can turn.

# LINCS and the Health & Literacy Special Collection

*William Hawk, Associate Director for LINCS*
*National Institute for Literacy*

*Sabrina Kurtz-Rossi, Project Director of Literacy and Health*
*World Education*

*Julie McKinney, Project Coordinator for the Health & Literacy Special Collection*
*World Education*

*Carolyn Staley, Deputy Director*
*National Institute for Literacy*

This presentation was divided into two segments. First, William Hawk, Sabrina Kurtz-Rossi, and Julie McKinney spent roughly one hour describing the Health & Literacy Special Collection, which is part of LINCS, the National Institute for Literacy's (NIFL's) searchable web-based resource for adult literacy practitioners. Then Carolyn Staley spoke for approximately 20 minutes regarding other activities underway at NIFL, and shared some of her general observations related to health literacy.

The Health & Literacy Special Collection is maintained by World Education with funding from NIFL; it contains information for use in teaching health topics to adults with limited literacy skills. The presenters explained that the LINCS Special Collections consist of a large database of materials grouped within eleven content areas, including Health & Literacy. Other content areas include English as a Second Language, Family Literacy, Literacy and Learning Disabilities, and Workforce Education. In addition to its Special Collections, the overall LINCS system includes on-line discussion groups, a calendar of events, basic facts and statistics about literacy, and a variety of other adult literacy resources. However, the presentation focused primarily on the Health & Literacy Special Collection, and included a detailed virtual tour demonstrating the content and functionality of the site. The Health & Literacy site is at http://www.worlded.org/us/health/lincs/

**Kurtz-Rossi** served in a moderator role, helping to coordinate **McKinney** and **Hawk's** presentation about LINCS and the Health & Literacy Special Collection. Areas discussed during the presentation include the following:

- **Resources available on health literacy**
  The Health & Literacy Special Collection contains a variety of literacy resources, which are broken into categories aimed at three groups: students and learners; teachers and tutors; and health care providers and health educators. Specific resources available include curricula, lesson plans, statistics, policy papers, an online discussion forum, a list of agencies and organizations, and a variety of links to other health literacy-related sites on the Internet. In addition, the site prominently features two documents published by World Education that serve as reference guides. These documents are the *Health and Literacy Compendium: An annotated bibliography of*

*print and Web-based health materials for use with limited-literacy adults* and *Culture, Health and Literacy: A Guide to Health Education Materials for Adults with Limited English Literacy Skills*. Both documents are available directly through the main Health & Literacy Special Collections URL.

- **Input sought**
  Although the Health & Literacy Special Collection currently includes a variety of health resources, the site is still under development and more input into what should be included is always welcome. Thus far, Hawk and McKinney have collected information on how students use the site (e.g., students prefer clicking to scrolling), and as a result they plan to revamp the site with more direct, easy-to-read health information. They noted that they are especially interested in finding out what sorts of information health and education professionals need to do their jobs effectively.

- **Parallels among LINCS Special Collections**
  The ten other Special Collections databases are structured in the same way as the health literacy collection, so once someone is acclimated to browsing one collection, the other collections become easy to navigate.

- **New developments**
  NIFL recently purchased an audio-visual server, which will allow the Special Collections sites to include items in addition to the text-based material currently available. However, video clips and other resources that require high bandwidth will be used on a limited basis, since not everyone has access to high speed Internet connections. Also, the designers are thinking about adding an information-sharing feature to the site to help facilitate communication among providers, and seek input on this idea.

Staley provided background information to detail how NIFL fits into the nationwide effort to address health literacy, and discussed NIFL's recent health literacy work:

- **Background of NIFL and LINCS**
  NIFL was created by the National Literacy Act of 1991, and has focused ever since on LINCS and other strategies that contribute to sharing resources and improving literacy services. LINCS is run through a national team, as well as five regional hubs across the U.S. that work more directly with individual states to build partnerships and facilitate resource sharing. In general, NIFL pursues health literacy and other issues by striving to serve as an information repository and a policy voice.

- **An agenda for action**
  NIFL has worked to address health literacy in various manners, including the creation of the Health & Literacy Special Collection and the health literacy listserv. In addition, the National Literacy Summit 2000 produced a white paper entitled "The Adult Literacy and Health Vision and Action Agenda," which is available online at http://www.worlded.org/us/health/lincs/agenda.htm. This paper stems from and

complements the overall National Literacy Summit 2000 Action Agenda, and is one of four focus papers commissioned by the NIFL summit. It is based on the belief that literacy and health must be addressed in conjunction, rather than through separate spheres. NIFL currently seeks input on the paper, in order to create a polished final draft.

- **Efforts to build momentum**
  In addition to refining the white paper, NIFL is holding ongoing conference calls and planning meetings to bring together health and literacy experts to help establish an action agenda for both fields. Once this agenda is crystallized, NIFL plans to move the agenda forward by taking it to key agencies, organizations, and others that work in the health literacy field. NIFL hopes to build on partnerships with the Division of Adult Education and Literacy, the American Medical Association, and other key stakeholders, in order to bring the agenda into practice.

## A View from the Field: A Health and Literacy Collaboration

*Dynishal Gross, Research Assistant*
*Adult Literacy Media Alliance*

*Jewel Mosley, Wellness Program Administrator*
*Health Education Center*

Dynishal Gross and Jewel Mosley spoke about the work being done by the groups for which they work, the Adult Literacy Media Alliance (ALMA) and the Health Education Center (HEC) respectively. ALMA is best known for its work producing the Emmy-winning television show TV411, which teaches literacy skills through an engaging format—"Sesame Street for adults," as Gross referred to the program. HEC is a non-profit affiliate of Highmark Blue Cross Blue Shield, which provides health education and wellness programs to uninsured, underinsured and underserved individuals in the Pittsburgh area. After describing ALMA and HEC, Gross and Mosley discussed their organizations' recent collaboration to create a health literacy program in the Pittsburgh area. This partnership was intended to expand HEC's offerings, in order to increase local residents' ability to understand health information and navigate the health care system. The presentation included clips from selected TV411 episodes, in order to demonstrate the kind of teaching methods the show includes.

Mosley provided a brief overview of several programs run by HEC:

- **HEC's free health improvement programs**
  HEC features the following programs in addition to its Health Literacy Program: Home Safe Home, which provides free fire extinguishers, child safety locks, and home safety education for families that include young children; Not Now!, a teenage pregnancy prevention program that targets girls who test negative for pregnancy at clinics; Healthy Families, which strives to empower caregivers to improve their health behaviors, in order to improve the health of their families; and HEC Scholarships, which allows people lacking financial resources to enroll in nutrition, smoking cessation, diabetes management, osteoporosis prevention, and other programs at no cost.

Gross highlighted some of the work being done by ALMA:

- **ALMA's efforts**
  TV411 is a 30 minute show—broadcast on over 100 PBS stations, which reach more than half of American households—that features a variety of styles (mini soap operas, documentaries, advertisements, etc.) in order to appeal to a broad audience of adult learners. The show aims to de-stigmatize adult learning, as well as to make learning fun and functional. ALMA produces other adult literacy projects to complement TV411, including a web site soon to debut, a print magazine that accompanies each episode of the show, and a video series featuring past shows. In addition, ALMA

works in partnership with community-based organizations across the U.S., such as the collaboration with HEC.

**Gross and Mosley** described the Health Literacy Program run by HEC with ALMA's assistance:

- **Background of the project**
  Over 200,000 adults in Allegheny County lack high school diplomas and few seek other educational programs, which is why Pittsburgh originally caught ALMA's attention. Meanwhile, HEC found that seniors in the area had many health literacy concerns, and that higher educational attainment did not always equate with health literacy. ALMA has been working with HEC since 1998 due to planning efforts by the Greater Pittsburgh Literacy Council, and has integrated its materials into all HEC programs. The Health Literacy Program was established in the Braddock borough due to the community's disproportionately high population of economically distressed seniors with low rates of educational attainment.

- **Why health literacy is a wise investment**
  Highmark Blue Cross Blue Shield has a business interest in health literacy because patients with lower health literacy are more likely to expend resources; for instance, they experience higher hospital recidivism rates. On the other hand, well-informed consumers make better patients, and better patients experience more successful health care outcomes. In short, educated consumers cost insurance companies less because they use health care resources more efficiently and make fewer claims.

- **Contents of the Health Literacy Program**
  Individuals who take part in the program must participate in six one-hour training sessions, and must complete work assignments outside of class (e.g., maintaining a health journal). TV411 materials, including videos, are incorporated into the classes, in addition to other health materials that are easily accessible to low-literacy participants. The TV411 videos are not all targeted at health issues, but lessons on filling out documents and other such topics are closely connected to health literacy. In addition, confidential health consultations are offered to participants one day per week, in order to help alleviate embarrassment about literacy problems.

- **Participants in the program**
  Participants in the program have ranged in age from 60 to 94 years old. They come from a wide range of literacy levels, as the program is open to all seniors in the area regardless of reading ability. In fact, the program does not formally screen for literacy problems although instructors may provide referrals to literacy tutors if they sense that a participant has the need. When an individual finishes the program, he or she receives a 20 dollar voucher to a local grocery store, an incentive to encourage course completion.

- **Program evaluation**
  The Health Literacy Program measures its success by conducting pre- and post-course surveys that assess participants using 17 items related to individuals' comfort with health issues. The instrument is designed to evaluate each participant's health risk and to measure if change has occurred six months after the completion of the program. Thus far, no data are available on the program's effectiveness because the program just began in June. Initial results are expected in the spring of 2002.

- **Upcoming initiatives**
  According to Gross, TV411 has received a grant to digitize all of its shows in order to make them available over the Internet. In addition, TV411 plans to incorporate more seniors into future episodes of the show, as current episodes feature primarily middle aged and younger actors. Mosley announced the Pittsburgh Health and Literacy Forum, which will be held in October; she said that people from across the country are welcome to attend and additional presenters may be needed.

# IV. Final Thoughts

Ronald Pugsley of DAEL asked participants to share their reflections on the symposium during a brief plenary session at the beginning of day two. In his comments opening the discussion, Pugsley shared his doubts about what he termed the prevailing paradigm that research is translated directly into practice. Instead, Pugsley argued: "I'm more and more convinced it's 'research to policy to practice'… research right into practice doesn't really happen that often… it has to go through a policy discussion at one level or another before it really, in a widespread way, becomes practice." He offered this view in order to encourage participants to discuss some of the policy implications of the information shared at the symposium, and to address the steps needed to move health literacy forward.

In addition to sharing personal anecdotes related to their work with health literacy, participants made comments that fall under the following broad themes:

- **Information sharing and partnerships are essential**
  There are cases where people from the same state have been working concurrently on health literacy projects yet remain unaware of one another's work. Others are working on similar health literacy projects in different states, and could benefit from dialogue with people who have faced similar challenges. Forums like this one and Pfizer's meetings are important because they help to disseminate information and resources, raise awareness, create networks, and build momentum. The U.S. Departments of Education and Health and Human Services, and other key stakeholders, must continue to increase their attention to health literacy, in order to model and facilitate means of information sharing and coalition building.

- **Barriers exist to educating health care practitioners**
  Physicians and nurses need to be educated about health literacy, especially since the issue is not typically addressed in medical and nursing school curriculums. Outside of the classroom, health care workers are incredibly busy and finding time to train them on health literacy is a difficult task. Health care programs should hire and fund more health educators, since they are excellent resources for addressing health literacy; however, money shortages and staffing cutbacks indicate that administrators often do not view health education as a top priority.

- **Further research is needed**
  While research indicates that health literacy is a serious concern, more work is needed to highlight the issue and to fully explain the effects of low health literacy. For instance, there is some solid information regarding the intersection between literacy and health, but there are currently little data on how health literacy affects individuals' preventive health practices. Another research area that needs further attention is the realm of international comparisons. Researchers need to develop "crosswalks" to make comparisons between U.S. and international data possible, in order to increase the availability of health literacy data.

Pugsley brought the symposium to a close with a few final words at the end of the second day. He thanked organizers and participants for their contributions, and urged them to reflect on ways to build upon ideas shared during the symposium. He implored participants to continue their own work and to think about ways they can pursue partnerships and other strategies to bring health literacy to a new level; in his words, to answer the question, "where do we go from where we are?"

# Appendix A:
# Presenter Biographies

# Appendix A – Presenter Biographies

This appendix contains biographical information submitted by symposium presenters. The biographies are in alphabetical order.

**Cynthia Baur** has her Ph.D. in Communication. She is a Senior Policy Advisor for e-health, and co-lead for the Health Communication Focus Area in Healthy People 2010 in the Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services.

Dr. Baur will discuss the Healthy People 2010 objective on health literacy. She will describe the Health Literacy Component of the National Assessment of Adult Literacy (NAAL) and its relevance for the objective and health communication and health literacy practice.

**Bob Bickerton** is the Director of Adult Education for the Commonwealth of Massachusetts. He has been an active player in the field of adult education for 30 years.

Prior to coming to the Department of Education thirteen years ago, Bob worked as an adult basic education (ABE) teacher, teacher trainer, curriculum developer, and program director. He has done this work in programs sponsored by a school system, a municipality, two colleges, and two community-based organizations.

Driven by a vision and an activist at heart, he has worked to strengthen, improve, and expand adult basic education services in the Commonwealth. Bob believes that administrators, teachers, community members and especially students MUST be partners for this work to be done well. Consequently, an effective and comprehensive system of ABE services is growing in Massachusetts along with state funding, which has increased 800 percent during his tenure.

Further, Bob has played a very active role at the national level, serving as legislative chair for both American Association for Adults in Continuing Education and the State Directors of Adult Education. During his four years as chair, he helped overcome momentum in Congress to eliminate ABE as a separate program and to build momentum for a common vision, including a long overdue increase in federal funding of almost 50 percent since fiscal year 1997! Most of all, he continues to have a vision that all under-educated and limited English proficient adults and their families can and will achieve their dreams and aspirations.

**Cecilia Doak**'s background in health education includes and M.P.H. from the University of Michigan and a 24-year career as a commissioned officer in the U.S. Public Health Service. She received the Surgeon General's Commendation Medal for her work in cancer education on the Pap smear and on smoking. She is the lead author of "Teaching Patients with Low Literacy Skills." The 2nd edition won a "Books of the Year" award by the American Journal of Nursing.

Ms. Doak has worked with Shoshone and Arapaho tribes in Wyoming where she lived for two years, and with health education teams in East and West Africa. Her experience also includes evaluating suitability of health education materials and testing the literacy skills of patients. For three years, she taught basic reading and writing to adults in Washington, D.C. She is currently and advisor to several government health agencies and to industry.

**Leonard Doak** comes to health education via adult education. For 14 years he was a volunteer tutor of non-readers. This experience carried over to his engineering work rewriting operating instructions for Navy ships and submarines. For two years he taught adults seeking their GEDs.

To further their work in health literacy, in 1978 he and his wife founded non-profit Patient Learning Associates. They have trained over 11,000 health care professionals, both throughout the U.S. and abroad. Together, they have analyzed over 2,000 health care instructions. They developed questionnaires and tested the suitability of health materials at clinics, hospitals and health centers.

They are currently working on health literacy projects with U.S. government agencies and with private industry.

**Dynishal Gross** is a graduate of Cornell University in New York City where she received her degree in Africana Studies. She is currently an assistant at Adult Literacy Media Alliance (ALMA). Ms. Gross is responsible for training and research pertaining to ALMA's community partners.

**William Hawk** is Associate Director for LINCS. He works on all NIFL's technology projects, and is a member of the Technology Team for the Equipped for the Future Initiative. He is a trained librarian and has also earned a master's degree in applied linguistics.

Prior to coming to NIFL in April 1999, Mr. Hawk worked as the Librarian for the Center for Literacy Studies in Knoxville, Tennessee. Since January 1994, when he first became a volunteer tutor, he has taught and tutored both ABE and ESL learners and has provided training for tutors, teachers, and program administrators on using technology in various content areas. Mr. Hawk has also worked as a program coordinator for a community-based literacy program.

**Cheryl Keenan** is currently Director of the Bureau of Adult Basic and Literacy Education in the Pennsylvania Department of Education, where she has been employed for the past 12 years, seven in her current positions. Ms. Keenan has over 25 years experience as an educator and holds a master's degree in education.

**Kristen Kiefer** is currently at the Center on an Aging Society at Georgetown University. Those of us working at the Center have done much work on health literacy over the course of the past four years, from analyzing the costs of low health literacy skills to identifying techniques being used to assist those with low health literacy skills as they navigate the complex health care system. In fact, we, in collaboration with the Center for Medicare Education, will be releasing a report about health literacy in August.

**Sabrina Kurtz-Rossi** has her master's degree in health education and has worked in a variety of community-based programs serving diverse populations.

She joined World Education eight years ago and has worked on many of the Literacy and Health Initiative projects. Ms. Kurtz is presently Director of the Health Education and Adult Literacy Breast and Cervical Cancer Project (HEAL:BCC), integrating health curriculum on breast and cervical cancer into adult basic education (ABE) and English for Speakers of Other Languages (ESOL) programs across the country; and the Health & Literacy Special Collection, designed to increase adult education practitioner access to health education materials and share information on the links between health and literacy with health care practitioners.

**Mark Kutner** is currently Project Director, National Assessment of Adult Literacy (NAAL). This project is developing the design for the 2002 NAAL, including developing an expanded background questionnaire and new cognitive items, and will analyze and report on findings from the assessment.

Dr. Kutner received his Ph.D. in Public Polciy from The George Washington University in Washington, D.C., and his M.P.A. in Public Administration from Syracuse University in New York. He obtained his B.A. in Political Science from Brooklyn College of the City University of New York.

**Kim Lee** is with the Georgia State Department of Education, Department of Technical and Adult Education. Ms. Lee is the Director of Assessment, Evaluation and the General Education Diploma (GED).

**Julie McKinney** is an experienced health and literacy educator. She began working with World Education four years ago as an education and training consultant for our Literacy and Health Initiative.

Ms. McKinney is presently the Project Coordinator for the Health & Literacy Special Collection. She has expertise as an English for Speakers of Other Languages (ESOL) teacher and has used health materials and the Internet in the classroom. She is committed to working with teachers to integrate health content into adult education curriculum and presently involves teams of adult learners and teachers in the evaluation and development of the Health & Literacy Special Collection.

**David Morgan** is a Professor at the Institute on Aging at the School of Community Health, Portland State University in Portland, Oregon. He received his doctorate in sociology in 1977, his master's degree in sociology in 1975, and his bachelor's degree in sociology in 1972, all at the University of Michigan.

**Jewel Mosley** has been the Wellness Program Administrator at the Health Education Center in Pittsburgh, Pennsylvania since March 1999. Her work is in the area of program development, implementation and evaluation. She develops programs for communities that are most at risk for the prevalence of chronic diseases.

Ms. Mosley has received the Best Practice Award from the National Black Leadership Initiative in Cancer, Morehouse School of Medicine, Atlanta, Georgia in 1998; Reaching People Through Partnerships Award from the National Cancer Institute in 1996; and Outstanding Community Member, WAMO Radio in Pittsburgh, Pennsylvania in 1996.

She has been active in the following professional and volunteer activities: the National Black Leadership Initiative in Cancer, where she served as Mid-Atlantic Region—Pittsburgh Chapter Chairman from 1996 to 1998, and Co-Chairman from 1993 to 1996; the Self-Help Group Network, where she worked on the Board of Directors in Pittsburgh from 1996 to 1999; and the African American United for Life Bone Marrow Donor Program, where she served as Recruitment Chairman from 1995 to 1997. Along with Maureen Reynolds, Ph.D., Ms. Mosley co-authored "Did You Know? The Truth About You, Your Baby and Drugs", which was published by St. Francis Hospital in 1990.

**Helen Osborne** is an occupational therapist, and has treated adults of all ages who are diagnosed with major mental illness. Ms. Osborne is also an educator and administrator, and has directed a health education department, taught health professionals about patient education, and developed and implemented patient education policy. She is a consultant, speaker, and writer, teaching health care professionals across the country ways to make medical information understandable.

She is the owner of Health Literacy Consulting where she assists organizations in communicating in ways customers and employees can understand—regardless of their language, literacy, age, or disability. She helps accomplish this by: consulting with organizations about ways to improve health care communication; training managers and employees about clear and simple communication strategies; writing and editing a wide variety of print and web-based documents; co-moderating NIFL-Health, an online discussion group about health literacy; and directing Health Literacy Month, a campaign to promote understandable health information.

Ms. Osborne has authored books such as *Overcoming Communication Barriers in Patient Education* and the forthcoming *Partnering with Patients to Improve Health Outcomes*. She has also published in numerous professional journals, as well as on the Internet and as a columnist for The Boston Globe's *On Call* magazine. Her professional credentials include membership in the American Writers Association, Institute of Management Consultants, National Speakers Association, and Women in Healthcare Management. She received her master of education degree in humanistic and behavioral studies from Boston University and her bachelor of science degree in occupational therapy from Tufts University.

**Scott Ratzan** is Editor-In-Chief for the *Journal of Health Communication: International Perspectives* and holds faculty appointments in the Department of Epidemiology and Public Health at Yale University, Department of Family Medicine and Community Health at Tufts University, and International Public Health at George Washington University.

Dr. Ratzan recently was principal author of "Attaining Global Health: Challenges and Opportunities." Other publications include "The Mad Cow Crisis: Health and the Public Good" and "AIDS: Effective Health Communication for the 90s." In 1999, his address on "Risk Communication" was selected in Vital Speeches of the Day. In 1998. his "Maxims for Effective Communication on Health and Risk Issues" were adopted as recommendations on dealing with food safety issues (e.g., eating beef) at a World Health Organization (WHO) consultation. He also has been a consultant to business and governmental agencies including the USDA on food safety, and the EPA on drinking water issues.

From 1998 to 2000, he has been Executive Director of Health Communication Technology and Educational Innovation at the Academy for Educational Development, where he worked with the WHO and Centers for Disease Control and Prevention on a variety of projects. From 1990 to 1998, he was founder and Director of the Emerson-Tufts Program in Health Communication, a joint master's degree program between Emerson College and Tufts University School of Medicine.

Dr. Ratzan has appeared on "Good Morning America," "Nightline" and other programs. He has published articles in numerous newspapers and journals (JAMA, etc.), and has served as medical advisory board chair for *Vitality* magazine. He received his M.D. at the University of Southern California; M.P.A. from the John F. Kennedy School of Government, Harvard University; M.A. from Emerson College; and his A.B. from Occidental College.

**Stephen Reder** is a University Professor and Chair of the Department of Applied Linguistics at Portland State University. His research interests include adult literacy and language development, adult education, and the interaction between culture and cognition.

Dr. Reder is currently directing two major national studies in adult education as part of the National Center for the Study of Adult Learning and Literacy. The Longitudinal Study of Adult Learning, an ongoing project, is closely following a population of adults over time and tracking changes in their literacy skills, formal and informal learning activities, and the personal, social and economic impact of those changes in adult life. The recently started Lab School for Adult ESL project is investigating second language acquisition and education among recent immigrants learning English.

Professor Reder is the author of numerous publication on these and related topics in adult literacy, education and language acquisition.

**Rima Rudd** is a faculty member in the Department of Health and Social Behavior, Harvard School of Public Health, where she also serves as director of educational programs. She teaches graduate courses that pertain to public health planning, program design, and evaluation as well as a course on health literacy.

Dr. Rudd is a researcher with the National Center for the Study of Adult Learning and Literacy and is the Principal Investigator for Health and Adult Literacy, and Learning which includes a group of studies focused on the relationships between health and literacy. She has designed and tested health curricula for adult learning centers, developed innovative materials supporting health literacy, and has produced a health literacy video and web page. She is the recipient for the first Pfizer Health Literacy Research Award.

**Joanne Schwartzberg** is Director of Aging and Community Health at the American Medical Association and Past President of the American Academy of Home Care Physicians. She has over 20 years of experience in home care as founder and Medical Director of one of the first multidisciplinary home health agencies in Chicago:

Chicago Home Health Service. She received her B.A. from Harvard and M.D. from Northwestern and is a Clinical Assistant Professor of Preventative Medicine and Community Health at the University of Illinois at Chicago College of Medicine. Dr. Schwartzberg is a past-president of the Institute of Medicine of Chicago and the Illinois Geriatrics Scoiety.

In 1988 she received the Physician of the Year Award from the National Association for Home Care. In 1992 she received the Physician of the Year Award from the American Academy of Home Care Physicians. In 1995 she served as co-chair of the Illinois Delegation to the White House Conference on Aging, Caucus on Health and Social Services. In 2000-2001, she has been a science adviser to the AMA Foundation's Health Literacy Initiative, and she has served as AMA liaison to the National Patient Safety Foundation's Partnership for Safe Medication Use—Educating and Empowering the Health Consumer. She is the 2001 recipient of the Henry P. Russe, M.D. "Citation for Exemplary Compassion in Healthcare" awarded by the Institute of Medicine of Chicago and the Rush-Presbyterian-St. Luke's Medical Center.

**Carolyn Staley** has served as the National Institute for Literacy's Deputy Director since 1994. She assists with general administration, advisory board matters, and program and policy development. She has directed NIFL's national public awareness campaign for literacy and manages the contract for the NIFL Hotline and Clearinghouse. Carolyn has established a number of important collaborations for NIFL, including the federal health-literacy partnership with the National Institutes for Health and the Centers for Disease Control and Prevention, and partnerships with the President's Summit on Service/America's Promise, America Reads, and the Corporation for National Service.

Before coming to NIFL, Carolyn served as the Executive Director of the Governor's Commission on Adult Literacy in Arkansas from 1991 to 1994. The Governor's Commission on Adult Literacy, created by then-Governor Bill Clinton in 1987, was one of the nation's earliest offices to promote collaboration across state government and the private sector for the support of literacy services and training for adults and families.

Prior to her work in the literacy field, Carolyn was Executive Director of the Arkansas Arts Council from 1979 to 1984 and Director of Touring Programs for the Arkansas Arts Center from 1986 to 1991. In 1985 she served as State Field Director for Hands Across America for Arkansas. An educator for 25 years, Carolyn has served on faculties at the University of Arkansas at Little Rock, Brescia College, Indiana University, St. Joseph" College, and Valparaiso University. Ms. Staley is married to Jerry Staley, an artist and photographer, and they are the parents of three young adults, Sarah, Mary, and Will.

**Heide Wrigley** is the Senior Researcher for Language, Literacy and Learning at Aguirre International, a minority-owned research and technical assistance firm. She is currently involved in a project for the Coalition of Limited English Speaking Elderly that brings together immigrants and refugees from Central Europe and Asia through an EL Civics Project in Chicago, funded by the U.S. Department of Education.

Her other work in health literacy has included a study for the Department of Public Health in Long Beach on health, language and culture issues in refugee resettlement, training for bilingual, bicultural health workers, and a course for English for Specific Purposes at the University of Southern California for nurses and doctors from Mainland China. She is on the advisory committee for the health literacy initiative to be developed by California Literacy. Heide holds a Ph.D. in education and an M.A. in applied linguistics.

# Appendix B:
# Symposium Participants, with Contact Information

## Appendix B – Symposium Participants, with Contact Information

The following individuals participated in the symposium either as presenters or registered attendees. U.S. Department of Education and other staff who supported the event are listed separately below.

**Participants[2]:**

**Amy Allen,** Senior Editor, Health Dialog. 617-854-7435; aallen@healthdialog.com

***Cynthia Baur,** Senior Policy Advisor, Office of Disease Prevention and Health Promotion. 202-205-2311; cbaur@osophs.dhhs.gov

***Bob Bickerton,** State Director of Adult Education, Massachusetts Department of Education. 781-338-3800; rbickerton@doe.mass.edu

**Kathy Bose,** Manager, Plain Language Service. 613-725-3769 x168; kbose@cpha.ca

**Judy Cooper,** ESL Specialist, Alabama Department of Education. 334-242-9109; jcooper@alsde.edu

**Carolyn Daher,** Student, Johns Hopkins School of Public Health. 401-523-2335; cdaher@jhsph.edu

***Cecilia Doak,** Director of Education, Patient Learning Association, Inc. 301-340-9894; Cecidoak@aol.com

***Leonard Doak,** President, Patient Learning Association, Inc. 301-340-9894; Lendoak@aol.com

**Al Emery,** Director, AHEC/Special Initiatives and Programs. 614-292-0716; emery-3@medctr.osu.edu

**Jeff Fantine,** Director, Central/Southeast ABLE Resource Center. 740-593-4419; fantine@ohio.edu

**Dianne Glass,** State Director of Adult Education, Kansas Board of Regents. 785-296-7159; dglass@ksbor.org

***Dynishal Gross,** Research Assistant, Adult Literacy Media Alliance. 212-807-4252; dgross@edc.org

***William Hawk,** Associate Director for LINCS, National Institute for Literacy. 202-233-2025; whawk@nifl.gov

**Wendy Hubenthal,** Student, University of Massachusetts – Boston. 617-559-0179; hubenthal@mediaone.net

***Carol Inge,** Director, Institute for Teaching Through Technology and Innovative Practices. 804-517-0717; cinge@longwood.lwc.edu

**Dora Johnson,** Research Associate, National Center for ESL Literacy Education. 202-362-0700; dora@cal.org

**Amy Jones,** Health Literacy Coordinator, Georgia Department of Technical and Adult Education. 404-679-1628; ajones@dtae.org

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[2] Asterisks denote presenters.

***Cheryl Keenan,** State Director of Adult Education, Pennsylvania Department of Education. 717-772-3737; ckeenan@state.pa.us

***Kristen Kiefer,** Research Associate, Center on an Aging Society at Georgetown University. 202-687-2471; kmk26@georgetown.edu

**Francie King,** Senior Editor, Health Dialog. 617-854-7427; fking@healthdialog.com

***Sabrina Kurtz-Rossi,** Project Director of Literacy and Health, World Education. 617-482-9485; skurtz@worlded.org

***Mark Kutner,** Project Director, National Assessment of Adult Literacy. 202-944-5300; mkutner@air.org

**Alden Lancaster,** Consultant in Contextual Adult Literacy. 301-270-2222; aldenwrite@aol.com

**Charlene Landis,** Pfizer, Inc. 212-733-4676; landic@pfizer.com

***Kim Lee,** Director of Assessment, Evaluation, and GED, Georgia Department of Technical and Adult Education. 404-679-1621; klee@dtae.org

**Marcia Martin,** Vice President, Gateway Health Plan. 412-255-4645; mmartin@gatewayhealthplan.com

**Nancy McKay,** Training Specialist, Northeast ABLE Research Center. 216-261-7076; resctr@ix.netcom.com

***Julie McKinney,** Project Coordinator for the Health & Literacy Special Collection, World Education. 617-482-9485; jmckinney@worlded.org

**Lennox McLendon,** Executive Director, National Adult Education Professional Development Consortium. 202-624-5250; lmclendon@naepdc.org

***David Morgan,** Professor, Institute on Aging, School of Community Health at Portland State University. 503-725-2345; morgan@pdx.edu

***Jewel Mosley,** Wellness Program Administrator, Health Education Center. 412-544-8430; jewel.mosley@highmark.com

**Maureen O'Connor,** Director of Programs and Services, Queens Borough Public Library. 718-990-8596; moconnor@queenslibrary.org

***Helen Osborne,** President, Health Literacy Consulting. 508-653-1199; Helen@healthliteracy.com

**Ursula Parker,** Program Specialist, Texas Education Agency. 512-463-9294; uparker@tea.state.tx.us

***Ronald Pugsley,** Director, Division of Adult Education and Literacy. 202-205-8270; ronald.pugsley@ed.gov

***Scott Ratzan,** Editor-in-Chief, Journal of Health Communication: International Perspectives. 202-712-5022; sratzan@aol.com

***Stephen Reder,** Professor, Institute on Aging, School of Community Health at Portland State University. 503-725-3999; reders@pdx.edu

**Sheila Rosenberg,** State Director of Adult Education, Texas Education Agency. 512-463-9264; srosenbe@tea.state.tx.us

**Diane Rosenthal,** Director, What Works Literacy Partnership. 646-237-0113; dianer@Literacypartners.org

**Rochelle Rubin,** Research Nurse Coordinator, Mt. Sinai School of Medicine. 212-241-0699; Rochelle.Rubin@MSSM.edu

***Rima Rudd,** Professor, Department of Health and Social Behavior at Harvard School of Public Health. 617-432-1022; rrudd@hsph.harvard.edu

**Lauren Schwartz,** Health Educator, NYC Poison Control Center. 212-447-2599; dsa212@nyu.edu

***Joanne Schwartzberg,** Director of Aging and Community Health, American Medical Association. 312-464-5000; Joanne_Schwartzberg@ama-assn.org

***Carolyn Staley,** Deputy Director, National Institute for Literacy. 202-233-2025; cstaley@nifl.gov

**Susan Sundell,** Education Programs Consultant, California Department of Education. 916-323-6769; ssundell@cde.ca.gov

***Yvonne Thayer,** State Director of Adult Education, Virginia Department of Education. 804-225-2075; ythayer@mail.vak12ed.edu

**Lisa Van Brackle,** Director of Program Development, Adult Literacy Media Alliance. 212-807-4238; lgale@edc.org

**Lauren Vitali,** Health Dialog. 617-854-7462; lvitali@healthdialog.com

**Heide Wrigley,** Senior Research Associate, Aguirre International. 650-373-4923; hwrigley@aiweb.com

DAEL and other symposium staff[3]:

**Toni Anderson,** Program Assistant, Division of Adult Education and Literacy (DAEL). 202-205-8270; toni.anderson@ed.gov

**April Blunt,** Program Analyst, DAEL. 202-690-5614; april.blunt@ed.gov

***Joyce Campbell,** Acting Branch Chief, DAEL. 202-205-5412; joyce.campbell@ed.gov

**Mike Dean,** Education Program Specialist, DAEL. 202-205-9294; mike.dean@ed.gov

**Phyllis Dorsey,** Program Analyst, DAEL. 202-205-9311; phyllis.dorsey@ed.gov

**Rickie Gallmon,** Program Assistant, DAEL. 202-205-9996; rickie.gallmon@ed.gov

**Joan Givens,** Education Program Specialist, DAEL. 202-708-9483; joan.givens@ed.gov

**Becky Hayward,** Chief Scientist, RTI International (RTI). 919-541-6811; bhayward@rti.org

***Kiawanta Hunter,** Education Program Specialist, DAEL. 202-205-9414; kiawanta.hunter@ed.gov

**Joyce Irving,** Management Analyst, DAEL. 202-205-8234; joyce.irving@ed.gov

**Karen Lee,** Program Assistant, DAEL. 202-205-9685; karen.lee@ed.gov

**Dan Levine,** Education Analyst, RTI. 919-485-5578; dlevine@rti.org

**Ursula Lord,** Education Program Specialist, DAEL. 202-205-5709; ursula.lord@ed.gov

***Ronald Pugsley,** Director, DAEL. 202-205-8270; ronald.pugsley@ed.gov

**Carol Rusaw,** Branch Chief, DAEL. 202-205-5451; carol.rusaw@ed.gov

**William Saunders,** Program Analyst, DAEL. 202-205-9233; william.saunders@ed.gov

**Jon Schmidt-Davis,** Education Analyst, RTI. 919-541-6285; jsd@rti.org

**Gloria Shade,** Program Analyst, DAEL. 202-205-5467; gloria.shade@ed.gov

***Julia Shepherd,** Deputy Director, DAEL. 202-205-9685; julia.shepherd@ed.gov

**Rose Tilghman,** Program Analyst, DAEL. 202-690-5848; rose.tilghman@ed.gov

***Carroll Towey,** Senior Advisor, DAEL. 202-205-9872; carroll.towey@ed.gov

***Cindy Towsner,** Education Program Specialist, DAEL. 202-205-5864; cindy.towsner@ed.gov

**Joyce Whalen,** Program Analyst, DAEL. 202-205-8959; joyce.whalen@ed.gov

***Glenn Young,** Education Program Specialist, DAEL. 202-205-3372; glenn.young@ed.gov

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[3] Asterisks denote moderators.

# Appendix C:
# Health Literacy Symposium Planning Committee

## Appendix C – Health Literacy Symposium Planning Committee

The following individuals were instrumental in planning for this symposium over the past few months:

**Kiawanta Hunter (Symposium Coordinator):** Division of Adult Education and Literacy, Washington, D.C.

**Cynthia Baur:** U.S. Department of Health and Human Services, Washington, D.C.

**Robert Bickerton:** State Department of Education, Malden, MA.

**John Comings:** National Center for the Study of Adult Learning and Literacy, Cambridge, MA.

**Mary Jo Deering:** U.S. Department of Health and Human Services, Washington, D.C.

**Jean Devard-Kemp:** State Department of Technical and Adult Education, Atlanta, GA.

**Phyllis Dorsey:** Division of Adult Education and Literacy, Washington, D.C.

**Dynishal Gross:** Adult Literacy Media Alliance, New York, NY.

**Becky Hayward:** RTI International, Research Triangle Park, NC.

**Marcia Hohn:** System for Adult Basic Education Support, Lawrence, MA.

**Dorothy Howe:** AARP, Washington, D.C.

**Sabrina Kurtz-Rossi:** World Education, Boston, MA.

**Kim Lee:** State Department of Technical and Adult Education, Atlanta, GA.

**Dan Levine:** RTI International, Research Triangle Park, NC.

**Nora Manzanares:** State Department of Education, Santa Fe, NM.

**Ruth Parker:** Emory University School of Medicine, Atlanta, GA.

**Ronald Pugsley:** Division of Adult Education and Literacy, Washington, D.C.

**Rima Rudd:** National Center for the Study of Adult Learning and Literacy, Cambridge, MA.

**Anthony Sarmiento:** National Senior Citizens' Education and Research Center, Inc., Silver Spring, MD.

**Joanne Schwartzberg:** American Medical Association, Chicago, IL.

**Carolyn Staley:** National Institute for Literacy, Washington, D.C.

**Judy Titzel:** World Education, Boston, MA.

**Lisa Van Brackle:** Adult Literacy Media Alliance, New York, NY.

# Appendix D:
# Accompanying Materials

# Appendix D – Accompanying Materials

Except for materials from a few presentations, which were submitted to RTI after the symposium, the items included in this appendix were distributed directly to symposium participants on August 1st and 2nd. We have made every effort to include as many of the pertinent materials that presenters distributed as possible, in order to supplement the summaries found in section III. However, space limitations caused us to exclude some lengthier materials from this report, and to reformat others (e.g., PowerPoint slides) to maximize available space. Materials are arranged in the order the presentations were made; please note that not all presenters had accompanying materials. Finally, web sites of the organizations presenters are affiliated with are listed if they were available.

Please contact presenters directly if you would like electronic copies of materials, or if you plan to make use of the materials (e.g., presentation notes) found here.

# Appendix D – Materials
# Leonard and Cecilia Doak's Presentation

*Web site:*
*N/A*

# Perspectives on Literacy and Health Literacy

Dept. Of Education
Washington, DC

Aug. 1, 2001

Cecilia C. Doak, MPH
Leonard G. Doak, PE
Patient Learning Assoc. Inc.
301 340-9894

# Perspectives:

## Health care views

- Goals are understanding and compliance
- Brief, episodic encounters
- Often seen as language or motivation problen
- Patient understanding is seldom evaluated
- Health care prof. not trained as teachers

# Perspectives

## Literacy and Adult Education Views:

- Goals are long term literacy skill development
- Continuous training for months and years
- Problem seen as a skill deficit
- Frequent evaluation of understanding and progress
- Well trained teachers (staff and volunteers)

# Communication Tasks:

**Medical people for patients:**

- Explain access to the medical system
- Obtain a complete medical history
- Explain a diagnosis
- Explain treatment options
- Explain medications, dosages, etc.

# Communication Tasks:

Adult Education and Literacy:

- Recruit and enroll students
- Teach literacy and numeracy skills
- Evaluate student progress
- Include wide topic materials: civics, health, etc.
- Student-teacher interaction is frequent and natural

# Areas for Collaboration:

Examples of Existing Collaborations:

- Easy-to-read health care print materials for patients and ABE
- Medical school use of low literacy pt simulation
- New NALS survey will include health questions
- “Healthy People 2010" literacy inputs
- Health education projects now include health educators and literacy contributors.

# Collaboration: Needs

- Develop models for collaboration for wide use
- Include collaboration requirements in new RFPs, RFQs
- Identify the tasks and literacy skills that are found in many common health care diagnoses
- Begin collaborations at this conference

# Communicating Access For Preventive Care (Mammograms)

**An Extra Step: Mammography**

Women in the three high risk categories—age 50 or more, age 40 or more with a family history of breast cancer, age 35 or more with a personal history of breast cancer— may consider an additional routine screening method. This is x-ray mammography. Mammography uses radiation (x-rays) to create an image of the breast on film or paper called a mammogram. It can reveal tumors too small to be felt by palpation. It shows other changes in the structure of the breast which doctors believe point to very early cancer. A mammographic examination usually consists of two x-rays of each breast, one taken from the top and one from the side. Exposure to x-rays should always be carried out to assure that the lowest possible dose will be absorbed by the body. Radiologists are not yet certain if there is any risk from one mammogram, although most studies indicate that the risk, if it does exist, is small relative to the benefit. Recent equipment modifications and improved techniques are reducing radiation absorption and thus the possible risk.

Original instruction based on the medical model.

(Source: Breast exams: What you should know. NCI/NIH, 1984.)

Readability: 12th grade

**What is a mammogram and why should I have one?**

A mammogram is an x-ray picture of the breast. It can find breast cancer that is too small for you, your doctor, or nurse to feel. Studies show that if you are in your forties or older, having a mammogram every 1 to 2 years could save your life.

**How do I know if I need a mammogram?**

Talk with your doctor about your chances of getting breast cancer. Your doctor can help you decide when you should start having mammograms and how often you should have them.

**Why do I need a mammogram every 1 to 2 years?**

As you get older, your chances of getting breast cancer get higher. Cancer can show up at any time—so one mammogram is not enough. Decide on a plan with your doctor and follow it for the rest of your life.

**Where can I get a mammogram?**

To find out where you can get a mammogram:

- Ask your doctor or nurse
- Ask your local health department or clinic
- Call the National Cancer Institute's Cancer Information Service at 1-800-4-CANCER

Revised instruction based on the Health Belief Model.

(Source: NCI/NIH, 1997)

Readability: 5th grade.

# Appendix D – Materials
# Scott Ratzan's Presentation

*Web site:*
*Journal of Health Communication* – ***http://www.aed.org/JHealthCom/***

Scott Ratzan also shared a couple of articles that we are unable to include here. These articles may be obtained using the information below:

- "Health Literacy: Making a Difference in the USA," from the *Journal of Health Communication*, provides some background information on health literacy and describes opportunities for action (including the need for federal initiatives); see the article online at http://www.aed.org/JHealthCom/V6/N2/editorial_v6n2.htm
- "Health literacy: communication for the public good," from *Health Promotion International* (Volume 16. Issue 2, pages 207-214), provides a more detailed treatment of health literacy, with a focus on the need for effective communication. The journal may be browsed online— http://heapro.oupjournals.org/ —although viewing full text articles requires a subscription; abstracts may be accessed for free.

## Health Literacy:
## Advancing the Public Good

U.S.Department of Education
August 1, 2001

**SCOTT C. RATZAN, MD, MPA, MA**

Editor-in-Chief, *Journal of Health Communication*

Senior Technical Advisor, U.S. Agency for International Development

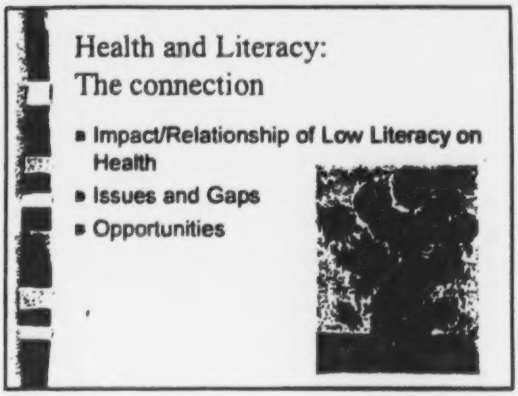
and

George Washington University School of Public Health

Tufts University School of Medicine

Yale University School of Epidemiology an Public Health

sratzan@aol.com; www.journalofhealthcommunication.com



## Health and Literacy: The connection

- Impact/Relationship of Low Literacy on Health
- Issues and Gaps
- Opportunities

## Health Literacy

- 90 million Americans are affected with low/marginal literacy
- Low literacy, poor health, and early death are inexorably linked
- Experts estimate that inadequate patient literacy skills increase national health-care costs by $75-100 billion per year

## Health Literacy consequences

- Less preventive health and early detection practices.
- Poor prenatal care and low birth weight
- 25 percent of women do not understand the difference between a Pap smear and a mammogram,
- 40 percent of patients do not understand what the common prescription label instruction "on an empty stomach"

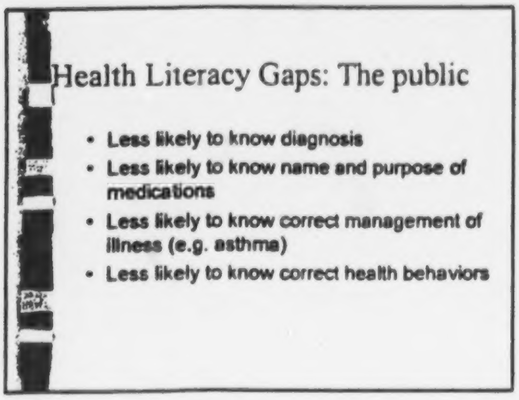
## Health Literacy: a unique entity

**Health Literacy is the capacity of individuals to obtain, interpret, and understand basic health information and services necessary for appropriate health decision-making.**

S. Ratzan, R. Parker , Editors, Current Bibliography of Medicine, National Library of Medicine, National Institutes for Health, 2000.

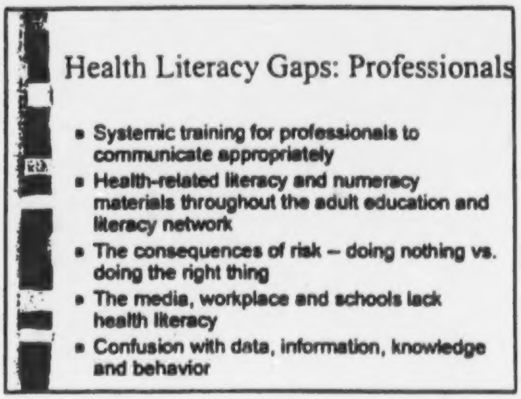
## What the definition means

- **Effective health communication is necessary for people to successfully navigate an increasingly complex health care system**



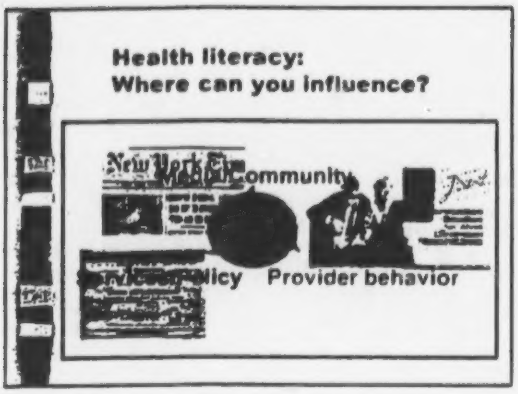
## Health Literacy Gaps: The public

- Less likely to know diagnosis
- Less likely to know name and purpose of medications
- Less likely to know correct management of illness (e.g. asthma)
- Less likely to know correct health behaviors

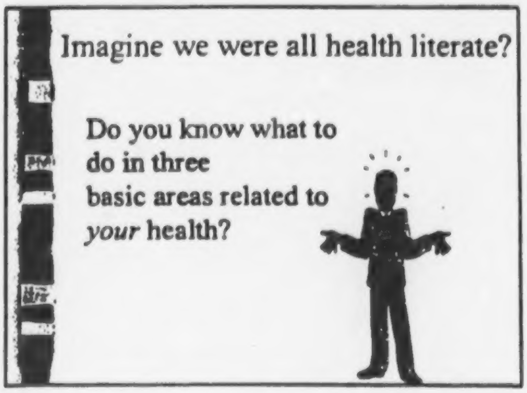


## Health Literacy Gaps: Professionals

- Systemic training for professionals to communicate appropriately
- Health-related literacy and numeracy materials throughout the adult education and literacy network
- The consequences of risk – doing nothing vs. doing the right thing
- The media, workplace and schools lack health literacy
- Confusion with data, information, knowledge and behavior

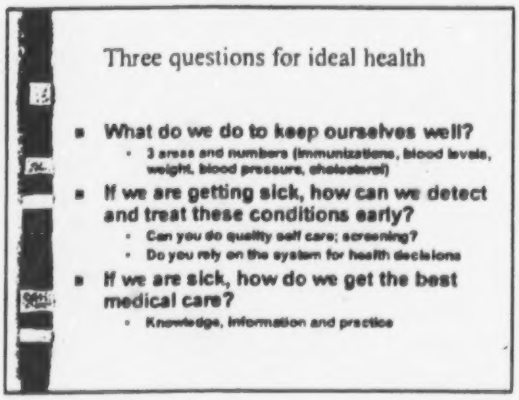


## Health literacy: Where can you influence?



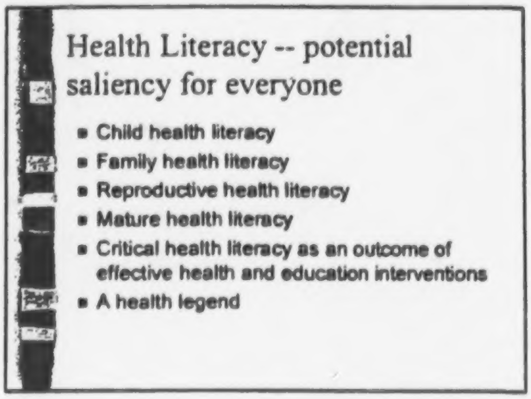
## Imagine we were all health literate?

Do you know what to do in three basic areas related to *your* health?



## Three questions for ideal health

- What do we do to keep ourselves well?
  - 3 areas and numbers (immunizations, blood levels, weight, blood pressure, cholesterol)
- If we are getting sick, how can we detect and treat these conditions early?
  - Can you do quality self care; screening?
  - Do you rely on the system for health decisions
- If we are sick, how do we get the best medical care?
  - Knowledge, information and practice



## Health Literacy -- potential saliency for everyone

- Child health literacy
- Family health literacy
- Reproductive health literacy
- Mature health literacy
- Critical health literacy as an outcome of effective health and education interventions
- A health legend

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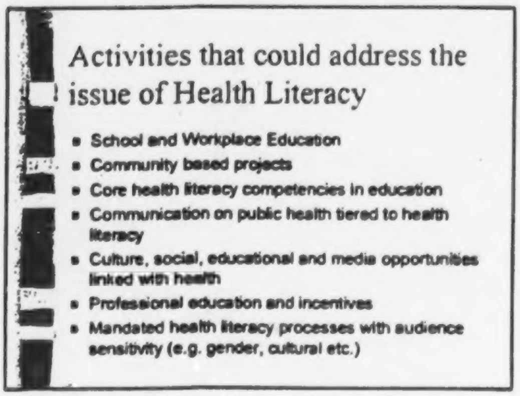
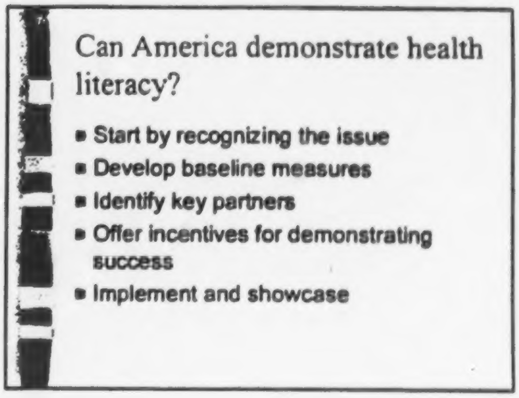


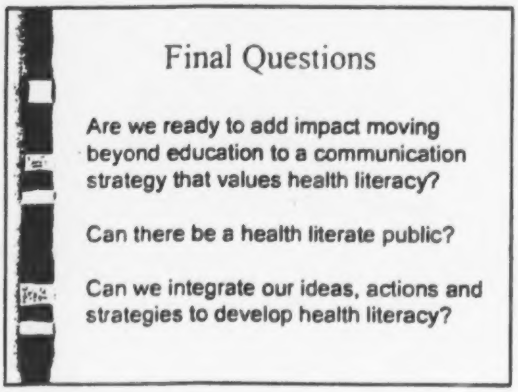
## Activities that could address the issue of Health Literacy

- School and Workplace Education
- Community based projects
- Core health literacy competencies in education
- Communication on public health tiered to health literacy
- Culture, social, educational and media opportunities linked with health
- Professional education and incentives
- Mandated health literacy processes with audience sensitivity (e.g. gender, cultural etc.)



## Can America demonstrate health literacy?

- Start by recognizing the issue
- Develop baseline measures
- Identify key partners
- Offer incentives for demonstrating success
- Implement and showcase



## Final Questions

Are we ready to add impact moving beyond education to a communication strategy that values health literacy?

Can there be a health literate public?

Can we integrate our ideas, actions and strategies to develop health literacy?

# Appendix D – Materials
# Rima Rudd's Presentation

*Web site:*
*Harvard Department of Health and Social Behavior –*
***http://www.hsph.harvard.edu/hsb/***

**Health Literacy Studies**

The Health Literacy Studies Group is comprised of faculty, graduate students, and professionals from fields of public health, medicine, and adult education. We are part of the National Center for the Study of Adult Learning and Literacy. We engage in a variety of activities, studies, and explorations linking health and literacy

[illegible] was produced by Rima Rudd, ScD and William DeJong, PhD of the Harvard School of Public Health, with the Health Literacy Studies group. Production was supported by the Pfizer Corporation, through an unrestricted educational award, and through the Educational Research and Development Centers Program, Award Number R309B60002, U.S. Department of Education

# In Plain Language

## The Need for Effective Communication in Medicine and Public Health

Health Literacy Studies
Harvard School of Public Health

NCSALL National Center for the Study of Adult Learning and Literacy

Disorder TUBERCULOSIS
Persistent cardiovascular
immunosuppressive congenital
EXAMINATION
confidential exertion
hospitalization UTERUS
murmur
PSYCHIATRIC cardiac
PROSTATE SINUS
arteriosclerosis

# In Plain Language

**Video Contents**

- Adults with low literacy skills share their experiences;
- Public health professionals discuss the impact of low literacy on health;
- Doctors talk about the role of literacy in interactions with patients;
- Practitioners focus on plain language;
- Researchers suggest communication strategies.

BEST COPY AVAILABLE

# In Plain Language

## The Need for Effective Communication in Medicine and Public Health

### Health and Literacy

■ **Functional Literacy**
Functional Literacy is the ability to use the written word for everyday tasks.

The 1992 National Adult Literacy Survey findings indicate that 47-51% of U.S. adults have limited or very low functional literacy skills.

■ **Health Literacy**
Basic health literacy includes the ability to obtain, interpret, and understand basic health information.

Health literacy also involves action—the ability to apply skills to health situations at home, at work, in the community, and in the policy arena.

A substantial body of research shows that the reading level of most written health materials far exceeds the reading ability of the average U.S. adult.

**TO ORDER A VIDEO**
email: **ncsall@worlded.org**
telephone: **617-482-9485 x535**

### Discussion Points

■ **For Medicine and Public Health**
What communication difficulties have you encountered in your work with clients and patients?

What is the literacy profile of the population groups with whom you work?

What communication strategies can you use to ease the burden on clients and patients?

■ **For Adult Education**
What health issues do your adult students face?

What is the health profile of the population groups with whom you work?

How can you help your adult students find the words to describe their health problems, access care, and improve community health?

■ **For Practitioners and Researchers**
How can we work together to strengthen health literacy?

# Adult Learners' Perspectives: Literacy and Health Issues

Rima E. Rudd
Health Literacy Studies
Harvard School of Public Health
National Center for the Study of Adult Learning and Literacy (NCSALL)

---

## NCSALL

NCSALL is the Department of Education's funded center for the study of adult learning and literacy

NCSALL pursues research to improve programs that provide educational services to adults who have low literacy and math skills, do not have a high school diploma, and/or do not speak English.

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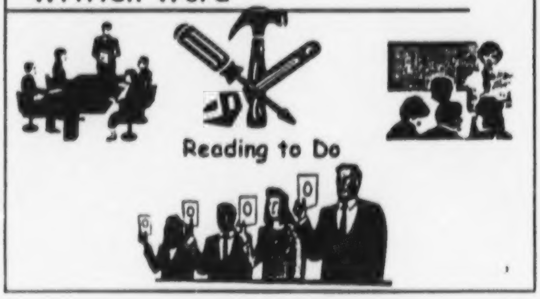
## Functional Literacy: Using the Written Word



Reading to Do

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## Schooling and Literacy

- Numeracy
- Time
- Directions
- Reading
- Vocabulary
- Descriptions
- Sequence
- Shared meaning

---

## Health Literacy

Health and Education
Functional Literacy
Health Literacy

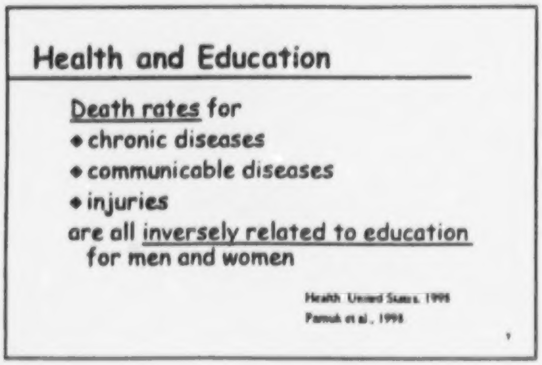
---

## Health and Social Position

Each increase in social position measured either by income or education improves the likelihood of being in good health.

This SES gradient was observed for persons of every race and ethnic group examined.

Health, United States, 1998
Pamuk et al., 1998

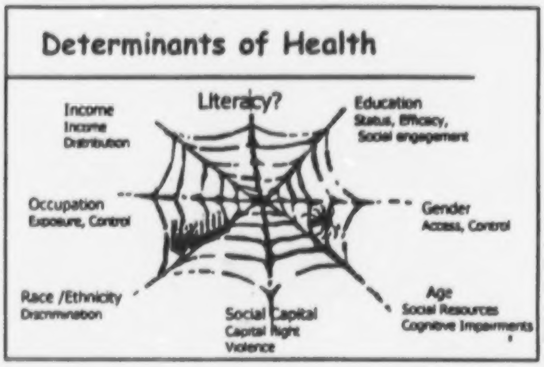


## Health and Education

Death rates for
- chronic diseases
- communicable diseases
- injuries

are all inversely related to education for men and women

Health United States 1998
Pamuk et al., 1998



## Determinants of Health

Literacy?

Education
Status, Efficacy,
Social engagement

Gender
Access, Control

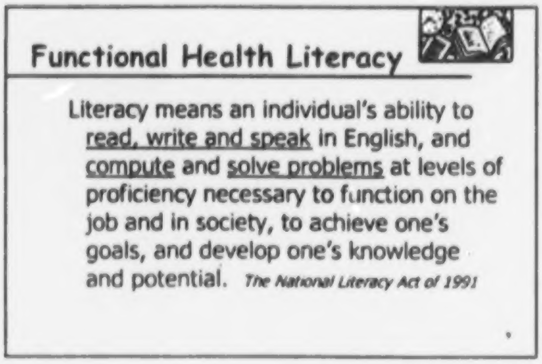
Age
Social Resources
Cognitive Impairments

Social Capital
Capital flight
Violence

Race /Ethnicity
Discrimination

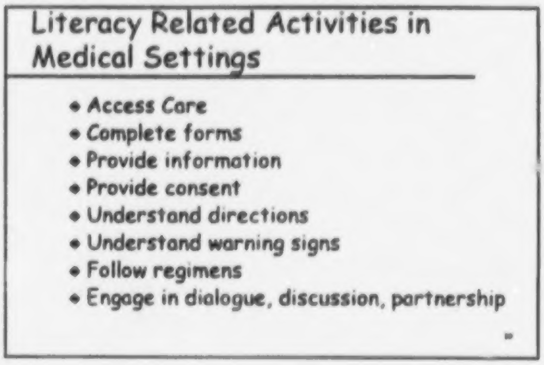
Occupation
Exposure, Control

Income
Income
Distribution



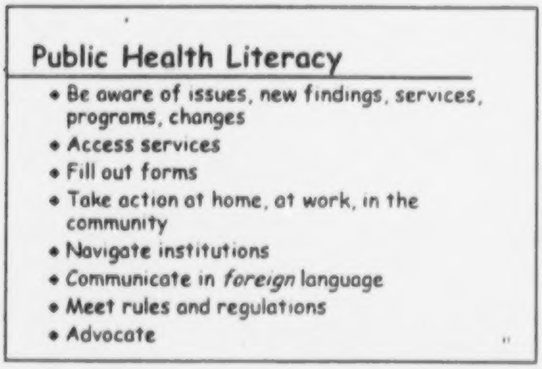
## Functional Health Literacy

Literacy means an individual's ability to read, write and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and develop one's knowledge and potential. *The National Literacy Act of 1991*



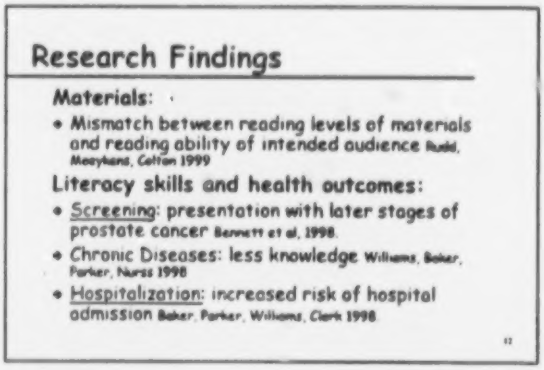
## Literacy Related Activities in Medical Settings

- Access Care
- Complete forms
- Provide information
- Provide consent
- Understand directions
- Understand warning signs
- Follow regimens
- Engage in dialogue, discussion, partnership



## Public Health Literacy

- Be aware of issues, new findings, services, programs, changes
- Access services
- Fill out forms
- Take action at home, at work, in the community
- Navigate institutions
- Communicate in *foreign* language
- Meet rules and regulations
- Advocate



## Research Findings

**Materials:**
- Mismatch between reading levels of materials and reading ability of intended audience Rudd, Moeykens, Colton 1999

**Literacy skills and health outcomes:**
- Screening: presentation with later stages of prostate cancer Bennett et al, 1998.
- Chronic Diseases: less knowledge Williams, Baker, Parker, Nurss 1998
- Hospitalization: increased risk of hospital admission Baker, Parker, Williams, Clark 1998

## Unexplored Areas

- Reading Level of health documents and research tools [questionnaires, informed consent, quality of care measures...]
- Literacy skills and social justice
- Links between literacy skills and oral comprehension
- Links between literacy skills and dialogue
- Literacy skills and awareness of / access to public health information and services

## NCSALL Health Literacy Studies

Public Health and Medical Settings
Adult Education Settings

## Health Literacy Studies

Setting: Public Health & Medicine

- Literature review
- Patients' Stories
- Navigation Issues
- Document Assessment
- Verbal Communication
- Media Access, Comprehension
- Patient Education Clinical Trial

## Health Literacy Studies

Setting: Adult Education

- Educators' Perceptions
- Learners' Perceptions & Experiences
- Health literacy skills
- Health Skills Curricula

## Adult Learner Perspectives

Studies: Interviews, Focus Groups, Stories, Walking tours, Requests for assistance

## Adult Learners' Perspectives

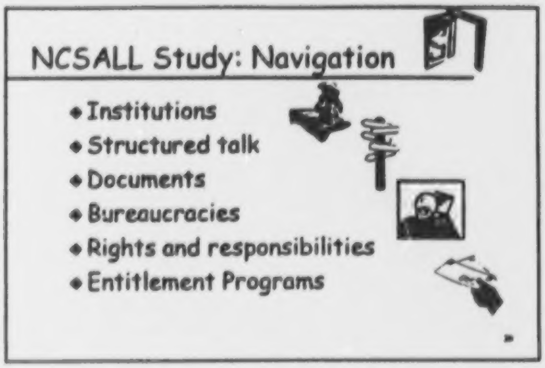
- Communication Problems
- Demands of the 'system'
- Needs: discussions, clarity, dignity, assistance
- Feelings

### NCSALL Study: Managing a Chronic Disease

Health Literacy Study: Patients' Stories [NCSALL report]

Chronic Disease Focus
- Asthma
- Osteoarthritis

Inquiry
- Story
- Issues



### NCSALL Study: Navigation

- Institutions
- Structured talk
- Documents
- Bureaucracies
- Rights and responsibilities
- Entitlement Programs

### Stories

- *I think that some of the words, they ought to put a parenthesis and tell them in English.*
- *Everybody hasn't gone through school and graduated... They should put it down so that if you went to 5th or 6th grade, you could understand.*

### Stories

*... I won't talk to someone who's not going to use words that are going to be easy to understand because he [the doctor] should know better.*

*If he starts using high medical terms that only someone that goes to medical college is going to know about, what's that say about him?*

### Stories

Managing Osteoarthritis:

*If I was going to complain, it would be taking 17 pills a day for one medical problem [osteoarthritis]. Now, that doesn't include my medication for hypertension, my medicine for hypothyroidism, a nasal spray for my allergic rhinitis.*

*So, you know...your life becomes a medical event...*

### Stories

Managing Asthma:

*I had to give up working. I had to give up what I had been doing for 27 years.... [crying]...*

*I just wasn't the same person.*

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## Voices for Action

Interviewer: *what has been the hardest part about learning to take care of your asthma?*

Informant: *Paying for it!*

## When Words Get in the Way

## When Words Get in the Way

- Lose your way
- Make errors
- Run out of words
- Retreat into silence
- Cover up / Lie
- Lose face
- Limit participation
- Assume/ be assigned a passive role
- Lose entitlements
- Lose rights

## Video

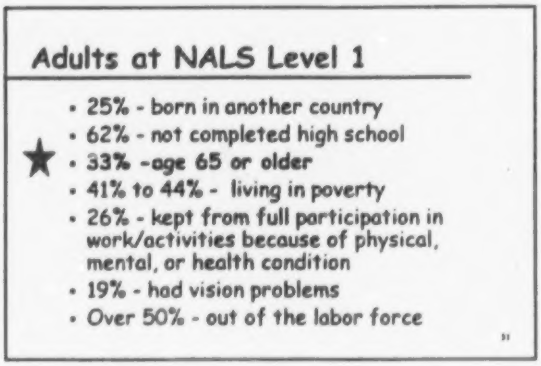
In Plain Language
The Need for Effective Communication in Medicine and Public Health

## Elders

Literacy
Health Related Issues
Health Literacy

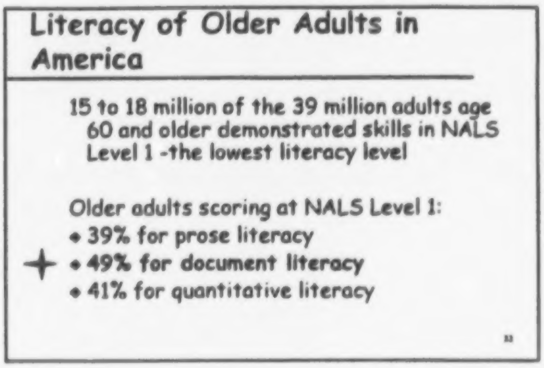
## Health of Older Adults

- Increased life expectancy
- 1 out of 10 living in poverty
- Prevalent chronic conditions
- Chronic diseases are the leading causes of death
- Major consumers of inpatient care
- High number of ambulatory care visits [mean 11.4 per year]
- Prevalent visual and hearing impairments



## Adults at NALS Level 1

- 25% - born in another country
- 62% - not completed high school
- ★ 33% -age 65 or older
- 41% to 44% - living in poverty
- 26% - kept from full participation in work/activities because of physical, mental, or health condition
- 19% - had vision problems
- Over 50% - out of the labor force

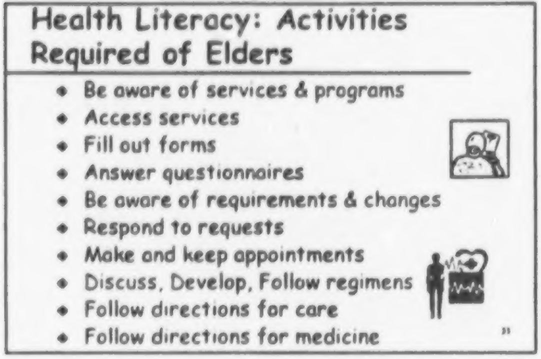


## Literacy of Older Adults in America

15 to 18 million of the 39 million adults age 60 and older demonstrated skills in NALS Level 1 -the lowest literacy level

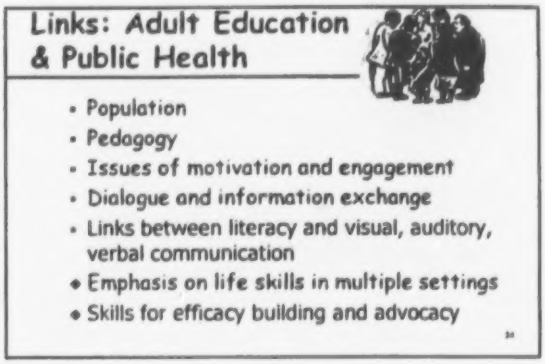
Older adults scoring at NALS Level 1:

- 39% for prose literacy
- ✛ **49% for document literacy**
- 41% for quantitative literacy



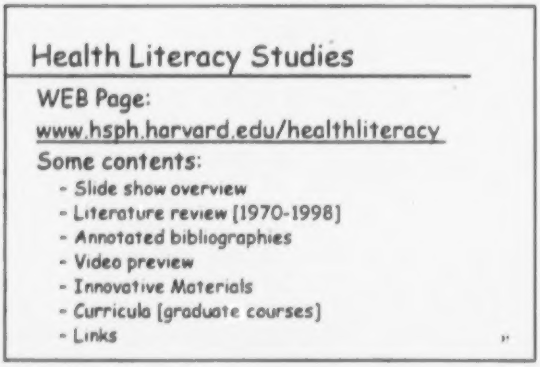
## Health Literacy: Activities Required of Elders

- Be aware of services & programs
- Access services
- Fill out forms
- Answer questionnaires
- Be aware of requirements & changes
- Respond to requests
- Make and keep appointments
- Discuss, Develop, Follow regimens
- Follow directions for care
- Follow directions for medicine



## Links: Adult Education & Public Health

- Population
- Pedagogy
- Issues of motivation and engagement
- Dialogue and information exchange
- Links between literacy and visual, auditory, verbal communication
- Emphasis on life skills in multiple settings
- Skills for efficacy building and advocacy



## Health Literacy Studies

WEB Page:

www.hsph.harvard.edu/healthliteracy

Some contents:

- Slide show overview
- Literature review [1970-1998]
- Annotated bibliographies
- Video preview
- Innovative Materials
- Curricula [graduate courses]
- Links

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# Appendix D – Materials
# Mark Kutner's Presentation

*Web site:*
*American Institutes for Research –* ***http://www.air.org***

NAAL 2002
National Assessment
of Adult Literacy

# National Assessment of Adult Literacy

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Presentation at the

## Health Literacy Implications for Seniors Symposium

August 1, 2001

Mark Kutner
Project Director, National Assessment of Adult Literacy
American Institutes for Research
mkutner@air.org

## What NAAL measures

- **Definition of Literacy**

  *Literacy is using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential.*

## What NAAL measures

- NAAL simulates the kind of focused reading tasks that individuals perform when they want specific information.
- NAAL items determine how effectively adults can search through texts of documents in response to specific probes.
- Questions precede the stimulus materials.

## What NAAL measures

- **Literacy tasks consist of actual materials adults in the United States encounter in their daily lives.**

| | |
|---|---|
| **Advertisements** | **Prescriptions** |
| **Instructions** | **Newspapers** |
| **Utility Bills** | **Order Forms** |

## What NAAL measures

- Dimensions of Literacy
  - *Prose Literacy.* Understanding and using information included in different types of texts such as newspaper articles, pamphlets, and fiction.
  - *Document Literacy.* Understanding and using information found in materials such as tables, application forms, and transportation schedules.
  - *Quantitative Literacy.* The knowledge and skills required to apply arithmetic operations, either alone or sequentially, to numbers embedded in printed materials such as check books.

## Whose literacy skills are being measured

- Nationally representative sample of adults 16 years of age and older
- Household national sample of 13,000 adults (planned)
- State samples of 1,000 adults from participating states (which may augment the national sample)
- Oversampling of African Americans and Hispanics

## Whose literacy skills are being measured

- Illustrative demographic characteristics without oversampling

| | |
|---|---|
| Older Americans | |
| Ages 55+ | 21 percent |
| Ages 65+ | 12 percent |
| Race/Ethnicity | |
| Hispanic | 13 percent |
| African Americans | 13 percent |
| Asian | 4 percent |

## How literacy is measured

- NAAL will include the seven blocks of items developed for the 1992 National Adult Literacy Survey and seven blocks of new items.
- NAAL will include approximately 45-50 items each in the prose, document, and quantitative dimensions (135-150 items) and approximately 45-50 stimulus materials.

## How literacy is measured

- Individually administered assessment, including:
  - 35 minutes collecting background information
  - 10 minutes of "core" easier items
  - 45-minute cognitive assessment consisting of three 15-minute blocks of items
- Respondents may take as long as they need to complete the assessment.

## Features Focusing on Low-Level Learners and ESL Adults

- Background questionnaire administered in Spanish
- Instruction for core cognitive items in Spanish for adults using the Spanish background questionnaire

## Features Focusing on Low-Level Learners and ESL Adults

- Supplemental Adult Literacy Assessment (ALSA) – a performance-based assessment for adults at the lowest literacy levels to get meaningful data about what these adults can do
- Skill profiles that provide a general literacy scale describing the cognitive skills and processes required to complete items

## NAAL and Health Literacy

- NAAL will provide information on health literacy, including:
  - A health literacy scale index score, including subgroup analyses
  - The relationship between adult literacy and knowledge of health topics
  - How materials related to the improvement of health can best be targeted to various population subgroups

## NAAL and Health Literacy

- Health section of Background Questionnaire:
  - General health status
  - Difficulty in seeing or hearing
  - Methods by which information on health topics are obtained
  - Preventive health activities, including flu shots, mammograms, colon and prostate cancer screening, osteoporosis screening, and dentistry
  - Understanding of materials related to health topics, including prescription drugs
  - Type of health insurance

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## NAAL and Health Literacy

- Approximately 14 cognitive items, two in each of the seven new blocks of items
- ALSA will use health-related items

## Illustrative NAAL Health Literacy Items

- Clinical activities
- Prevention activities
- Navigating health system

## How NAAL Health Literacy Data will be reported

- Results from the HLC items will be presented as a health literacy index score.
- Results will be presented according to demographic characteristics, such as race, gender, and income to highlight disparities.
- Health background information will be analyzed in conjunction with the health literacy scale.

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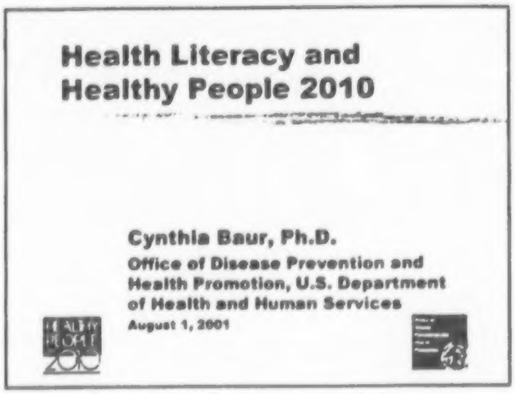
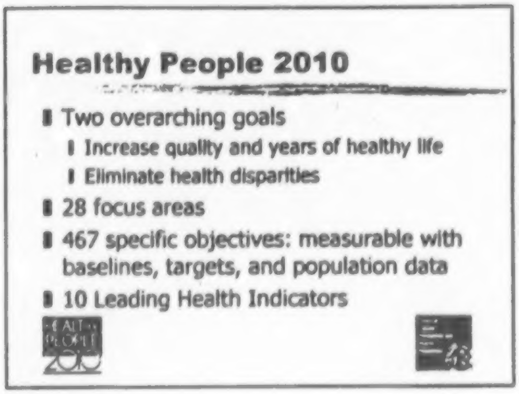
# Appendix D – Materials
# Cynthia Baur's Presentation

*Web site:*
*U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion* – ***http://odphp.osophs.dhhs.gov/***



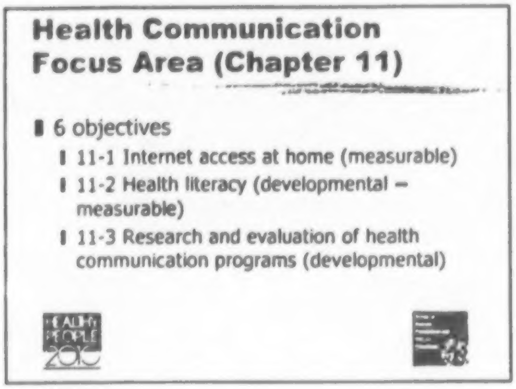
## Health Literacy and Healthy People 2010

**Cynthia Baur, Ph.D.**
**Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services**
**August 1, 2001**



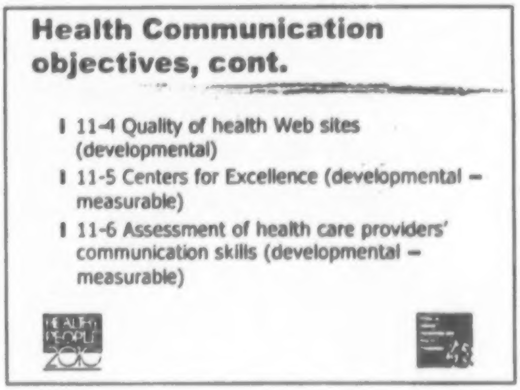
## Healthy People 2010

- Two overarching goals
  - Increase quality and years of healthy life
  - Eliminate health disparities
- 28 focus areas
- 467 specific objectives: measurable with baselines, targets, and population data
- 10 Leading Health Indicators



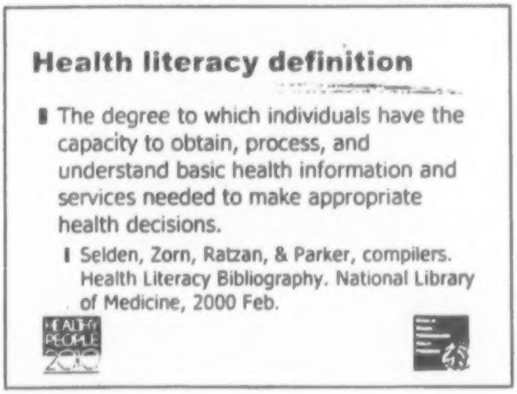
## Health Communication Focus Area (Chapter 11)

- 6 objectives
  - 11-1 Internet access at home (measurable)
  - 11-2 Health literacy (developmental – measurable)
  - 11-3 Research and evaluation of health communication programs (developmental)



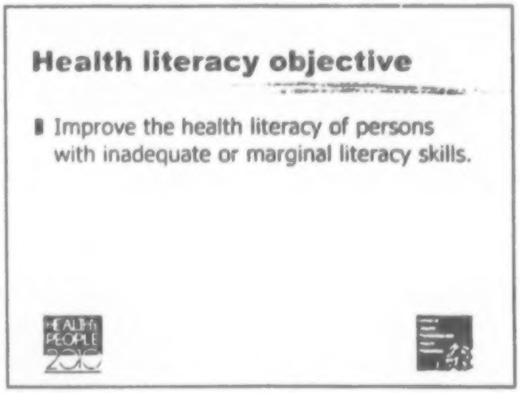
## Health Communication objectives, cont.

  - 11-4 Quality of health Web sites (developmental)
  - 11-5 Centers for Excellence (developmental – measurable)
  - 11-6 Assessment of health care providers' communication skills (developmental – measurable)



## Health literacy definition

- The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.
  - Selden, Zorn, Ratzan, & Parker, compilers. Health Literacy Bibliography. National Library of Medicine, 2000 Feb.



## Health literacy objective

- Improve the health literacy of persons with inadequate or marginal literacy skills.

## Health Literacy Component of 2002 NAAL

- Elicit respondents' knowledge and skills to locate and understand health related information and services
- Block of items distributed across each of the 7 new NAAL cognitive assessment blocks
- Results: health literacy index score according to demographic characteristics

## Scope of stimulus material and items

- Domains: clusters of key types of health and health care information and services that the general population in the U.S. might be likely to encounter

## Three domains

- **Clinical**
  - **Ex: filling out a patient information form for a doctor's office visit**
- **Prevention**
  - **Ex: deciding to get an influenza vaccination at the beginning of the flu season**
- **Navigation of the health care system**
  - **Ex: understanding co-pays and deductibles in health insurance plans**

## Conclusions

- Health literacy improvements are key to a reduction in health disparities.
- If appropriate materials exist and individuals receive the training to use them, then measurable improvements in health literacy can occur.

# Appendix D – Materials
# State Directors' Panel Presentation

*Web sites:*
*Georgia* – ***http://www.dtae.org/adultlit.html;***
*Massachusetts* – ***http://www.doe.mass.edu/acls/;***
*Pennsylvania* – ***http://www.pde.psu.edu/able/index.html;***
*Virginia* – ***http://www.pen.k12.va.us/VDOE/Instruction/Adult/index.html***

State directors of adult education distributed some materials that could not be included here due to space constraints. Please refer to the list below for some of these additional resources:

- The Massachusetts Prevention Center Resource Library Central Catalog, which contains records for 11 health education libraries, can be accessed online at http://www.state.ma.us/dph/mpc/

- The Spring 2001 edition (Vol. 10, No. 4) of *Field Notes,* the quarterly newsletter published by SABES with funding from the Massachusetts Department of Education, contains articles and resources for teaching health and literacy. It is available online at http://www.sabes.org/fn104.htm

- The Virginia Adult Education Technology Plan, which Yvonne Thayer and Carol Inge distributed on disc at the symposium, is available online at http://optimus.ed.vt.edu/tsmith/institute/Images/AdultEdTechPlan.pdf

Georgia Department of Technical and Adult Education
Office of Adult Literacy

# HEALTH LITERACY ADVISORY COMMITTEE

Richard Andersen
AARP, Georgia State Office

Dahna Batts-Osborne, M.D.
Centers for Disease Control
Center for Environmental Health

John Berglund, Executive Director
GA Academy of Family Physicians

Dr. Ronald Braithwaite
Emory University
Rollins School of Public Health

Vena R. Chrichlow-Scales, M.A.
Department of Human Resources
Div. of Public Health/Family Health

Walter Falconer, M.D.
Urology

Rhunette Flowers, M.D.
Pediatrics

Gregory Fricchione, M.D.
Psychiatry
The Carter Center

Nelda Greene
Georgia Dental Association

Marcia Griffith, M.P.H.
Program Manager
ZAP Asthma Program

Frenessa K. Hall, M.D.
Internal Medicine

Buddy Harden,
Executive Vice President
GA Pharmacy Association, Inc.

Emerson Harrison, M.D.
Urology
DeKalb Medical Center

Kara L. Jacobson, MPH, CHES
Health Behavior & Education Specialist
USQA Center for Health Care Research

Dr. Barbara Melichar, Director
SDA #4 - North Georgia Technical College

Dr. Joanne R. Nurss,
Professor Emeritus
Georgia State University

Ruth Parker, M.D.
Department of Medicine
Emory University School of Medicine

Megan Reif
Assistant Director of Development for Health Programs
The Carter Center

Dr. Kim Richards

Mr. Patrick Rossiter, Director
SDA #24 - Richard Arnold Adult Education Center

Deborah Smith-Callahan, Director
State Government Relations, Pfizer, Inc.

Darryl J. Tookes, M.D.
Georgia Surgical Professional
Associates

Adewale Troutman, M.D.
Director, Fulton County Department of Health and
Wellness

Dr. Reuben C. Warren
Associate Administrator for Urban Affairs
Agency for Toxic Substances and Disease Registry

Mark V. Williams, M.D.
Associate Professor of Medicine
Emory University School of Medicine

Georgia Department of Technical and Adult Education
Office of Adult Literacy

# The Health Literacy Initiative

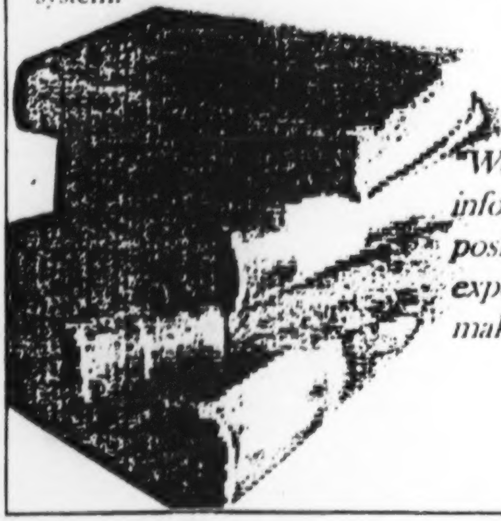
*"This is my first Teachers' Academy and I was very impressed.... Wonderful information!"*

Each year, the Office of Adult Literacy organizes a statewide Teachers' Academy. The Academy has become one of the most effective means of providing training and instruction to Georgia's Adult Literacy instructors. In 2001, the focus of the Teachers' Academy was Georgia's new Health Literacy Initiative. We invited some of the nation's most respected health care professionals to provide the foundation upon which Georgia's adult literacy teachers will build an integrated adult literacy curriculum that will allow adult learners to read, understand, and act on health care information.

The Academy faculty demonstrated an unparralleled dedication to education. Through presentations, workshops, and panel discussions, the following was covered:

- HIV/AIDS
- Mental Health
- Diabetes
- Community Health
- Oral Health
- Internal Medicine
- Heart Disease
- Breast Cancer

Over 160 of Georgia's full-time adult literacy Teachers were present at the Academy. Together, the people attending this year's Teachers' Academy exemplified the talent and courage that will be necessary to awaken the health care community and the adult literacy community to the issues that low-level readers face when dealing with the health care system.



*"We are not asking our teachers to become health information specialists. We want to put them in a position to combine their adult literacy teaching expertise with the health content. That's what makes our program unique."*

*- Amy Jones, RN*
*Health Literacy Coordinator*
*Office of Adult Literacy*

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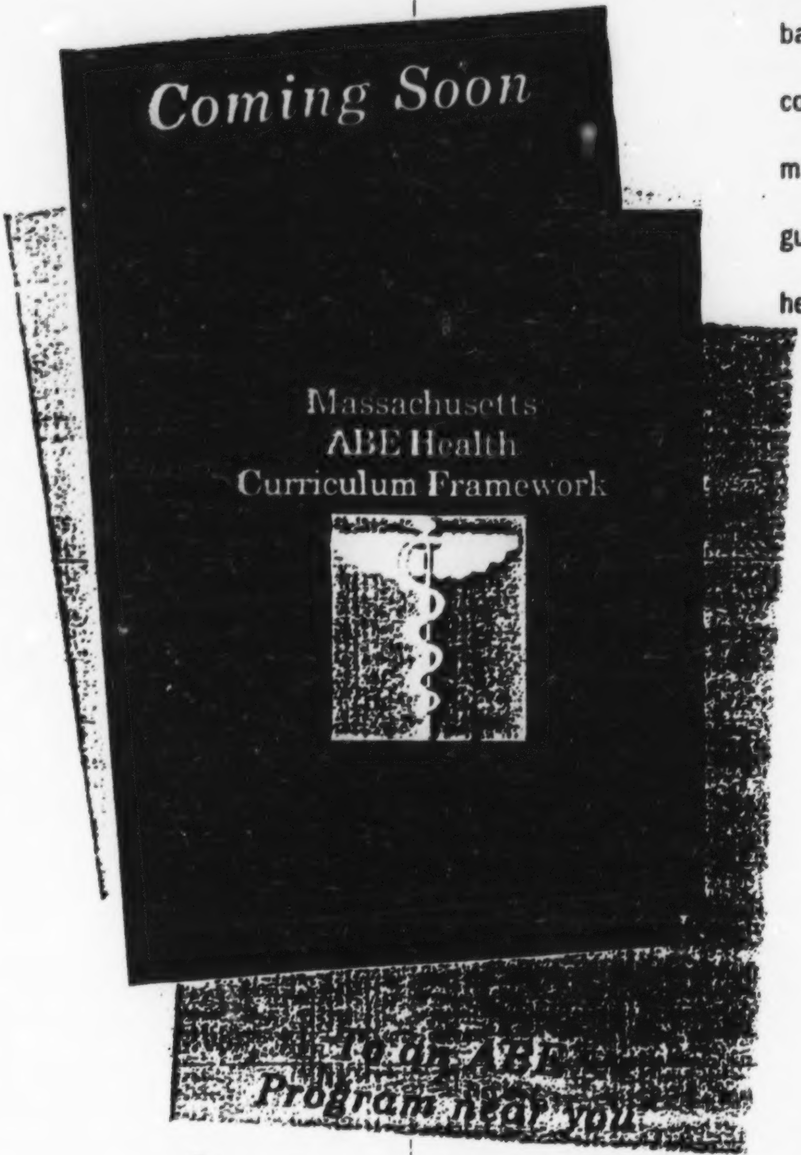

**The Massachusetts ABE Health Curriculum Framework 2001 Revision will be available this fall. The framework is designed to assist adult basic education programs to integrate health content into English Language Arts, Mathematics, and English for Speakers of Other Languages curricula. The frameworks provide health related information including:**

- *Core concepts*
- *Guiding Principles*
- *Habits of Mind*
- *Content Strands and Standards*
- *Strategies for integrating health content into ABE/ESOL classes*
- *Strategies for using technology in instruction*
- *Resources and a bibliography*
- *Internet resources*

Written for Massachusetts ABE practitioners by ABE curriculum developers and health education experts with contributions from ABE educators from across the Commonwealth.

Other Massachusetts ABE Curriculum Frameworks include:

- Common Chapters
- English Language Arts
- Mathematics
- ESOL
- Science and Technology
- History and Social Science

For copies of the Massachusetts ABE Curriculum Frameworks go to http://www.doe.mass.edu/acls or call Robert Foreman at MADOE (781) 338-3815

*Massachusetts Department of Education*
*Adult and Community Learning Services*
*350 Main Street*
*Malden, MA 02148*
*(781) 338-3000*

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# Georgia Department of Technical and Adult Education
## Office of Adult Literacy
## Proposed Design – Health Literacy Pilot Project
**March 8, 2001** *(Revised July 10, 2001)*

**Implementation: July 1, 2001 (Fiscal Year 2002)**

### *What is Health Literacy?*

***"Health Literacy is the ability to read, understand, and act on health care information. Functional health literacy is the ability to apply reading and numeracy skills in a health care setting. A patient/student must be able to comprehend the concepts and tasks necessary to meet his/her health care needs. These include being able to:* READ *consent forms, medicine labels and inserts, and other written health care information;* UNDERSTAND *written and oral information given by physicians, nurses, pharmacists, and insurers, and* ACT *upon necessary procedures and directions such as medication and appointment schedules."***

***Center For Health Care Strategies***

### Activities

**Teachers' Academy 2001 – Health Literacy**

The Teachers' Academy will be designed to address two strands: "Integrating Health Literacy with the ABE and ELP Curriculums" and *"Developing and Implementing Health Literacy Programs."* Teachers attending the Academy not associated with Pilot Centers will address the former strand and Pilot Center Teachers will address the latter strand. Upon completion of the Academy participants will be able to:

- **Examine definitions and implications of functional health literacy and health literacy measures;**
- **Assess methods and findings of studies linking literacy and health outcomes;**
- **Use and analyze the Test of Functional Health Literacy (TOFLA);**
- **Consider collaborative work between the fields of adult literacy and health education;**
- **Identify local community resources and establish communication links with the health care community; and**
- **Identify and/or develop health related materials for instruction.**

Proposed sub-topics for the Academy include:

- **Assessing Students' Functional Health Literacy & Evaluating Progress**
- **Methodology for Developing Health Literacy Student Education Plans**
- **Effective Health Literacy Instructional Strategies**
- **Navigating the health care community: How to prepare students**
- **Focus Areas: HIV/AIDS, Diabetes, Heart Disease, Breast Cancer and Oral Health (*emphasis on Hypertension)**

### OAL Responsibilities

- General oversight of project
- Evaluation methodology design
- Monitor Progress
- Secure evaluator

### Pilot SDA Responsibilities

- Identify part-time teachers for Health Literacy and register them for the Academy
- Provide feedback
- Adhere to all policies, procedures and reporting requirements of the project
- Other, as determined by the project.
- Identify and secure sites for Health Literacy classes according to the following matrix

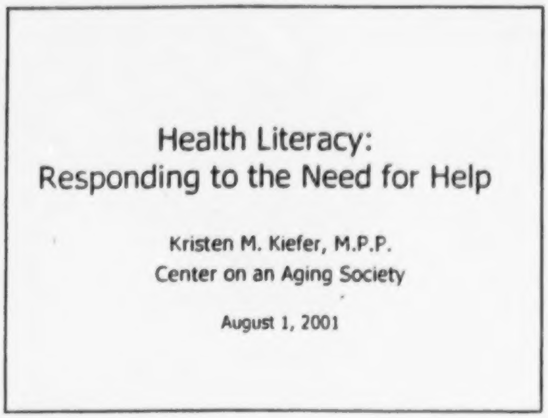
| SDA # | 4 | 10 | 14 | 18 | 24 | 27 | 31 |
|---|---|---|---|---|---|---|---|
| # Sites* | 1 | 3 | 2 | 1 | 2 | 3 | 1 |

*subject to change

*Total: 13*

# Appendix D – Materials
# Kristen Kiefer's Presentation

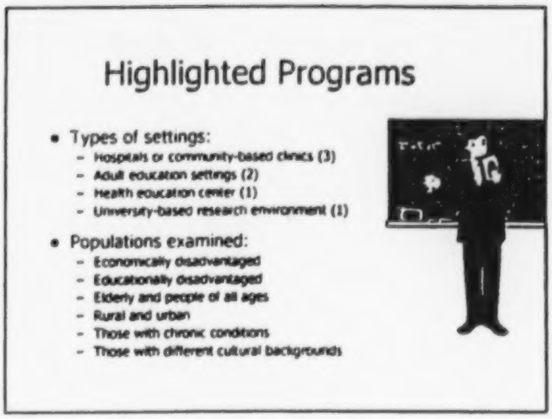
*Web site:*
*Georgetown Center on an Aging Society –*
*http://www.georgetown.edu/research/ihcrp/agingsociety/*



## Health Literacy: Responding to the Need for Help

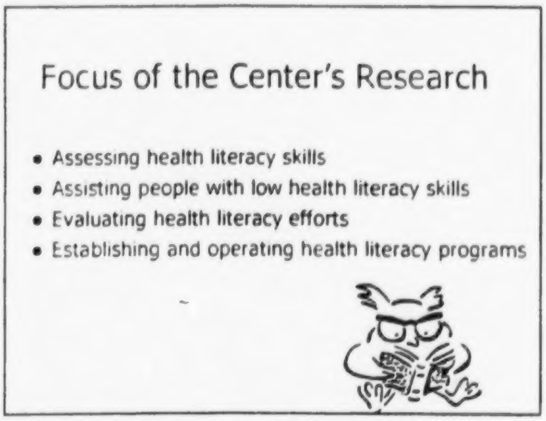
Kristen M. Kiefer, M.P.P.
Center on an Aging Society

August 1, 2001



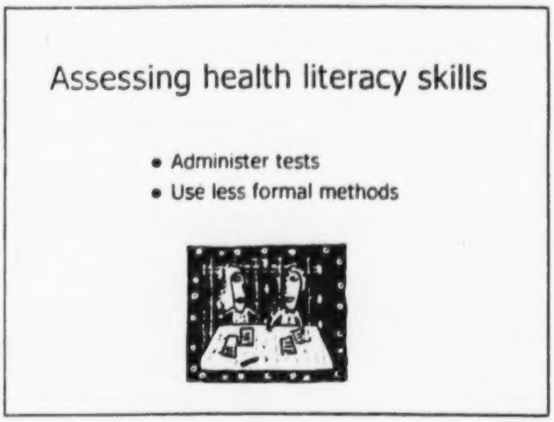
## Highlighted Programs

- Types of settings:
  - Hospitals or community-based clinics (3)
  - Adult education settings (2)
  - Health education center (1)
  - University-based research environment (1)
- Populations examined:
  - Economically disadvantaged
  - Educationally disadvantaged
  - Elderly and people of all ages
  - Rural and urban
  - Those with chronic conditions
  - Those with different cultural backgrounds



## Focus of the Center's Research

- Assessing health literacy skills
- Assisting people with low health literacy skills
- Evaluating health literacy efforts
- Establishing and operating health literacy programs



## Assessing health literacy skills

- Administer tests
- Use less formal methods

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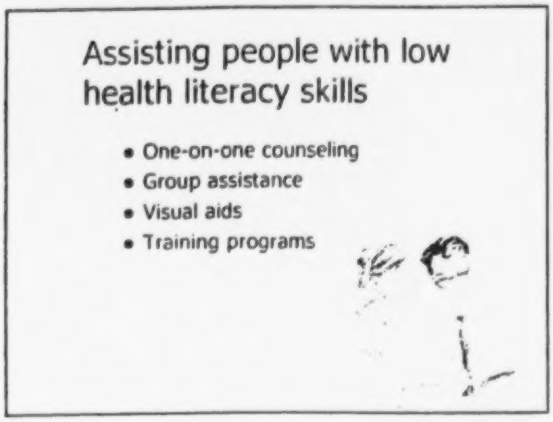
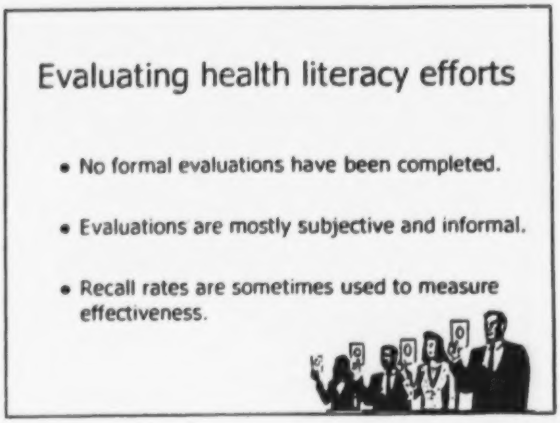


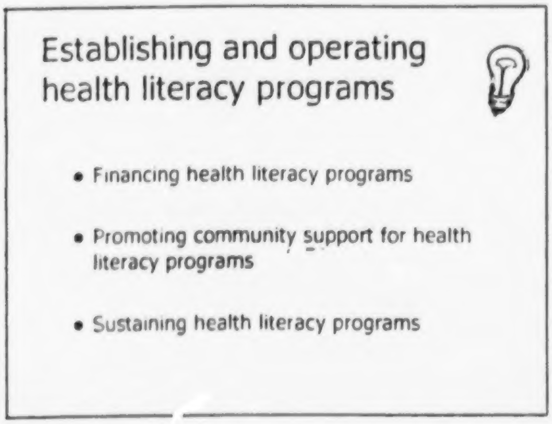
## Assisting people with low health literacy skills

- One-on-one counseling
- Group assistance
- Visual aids
- Training programs



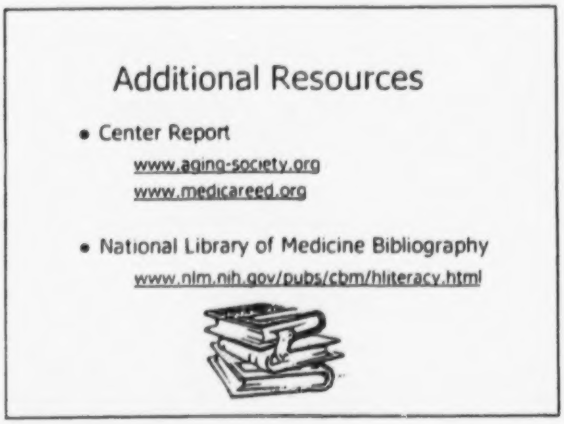
## Evaluating health literacy efforts

- No formal evaluations have been completed.
- Evaluations are mostly subjective and informal.
- Recall rates are sometimes used to measure effectiveness.



## Establishing and operating health literacy programs

- Financing health literacy programs
- Promoting community support for health literacy programs
- Sustaining health literacy programs



## Additional Resources

- Center Report
  www.aging-society.org
  www.medicareed.org
- National Library of Medicine Bibliography
  www.nlm.nih.gov/pubs/cbm/hliteracy.html

# Appendix D – Materials
# Joanne Schwartzberg's Presentation

*Web site:*
*American Medical Association –* ***http://www.ama-assn.org***

# Low Health Literacy:
# The Hidden Risk

**Joanne G. Schwartzberg, MD**
**American Medical Association**

## Definition

Health Literacy is the ability to read, understand and act on health care information

Why is the patient's health literacy a critical factor in 21st century medicine?

## Changes in the Health Care System

| | 30 Years Ago | Today |
|---|---|---|
| Treatment of Acute Myocardial Infraction | •6 weeks bed rest in hospital | •2-4 days in hospital (M&R Guidelines) |
| Available Prescription Drugs | •650 | •10,000 + |
| Treatment of new onset diabetes | •3 weeks in hospital<br>2 hours a day of diabetic education classes | •outpatient<br>0-3 hours diabetic education classes<br>written materials<br>internet<br>telemedicine |

## Changes in the Health Care System

| | 30 Years Ago | Today | |
|---|---|---|---|
| Available Sites of Care | •Hospital<br>•Office<br>•Own Home<br>•Homes for the Aged | • Hospital<br>- ICU<br>- Step down<br>- Extended care<br>• Nursing facility<br>- Subacute<br>- Skilled<br>- Intermediate | • Assisted Living<br>• Rehabilitation Hospital<br>• Chronic Disease Hospital<br>• Home Care<br>• Home Health Care<br>• Group Homes<br>• Foster Care<br>• Telemedicine |

## National Adult Literacy Survey

- n = 26,000
- Most accurate portrait of literacy in U.S.
- Scored on 5 levels

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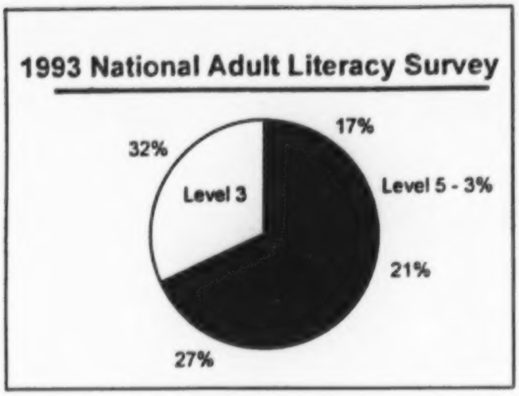


## 1993 National Adult Literacy Survey

## NALS Level 1

**CAN**

- Sign Name
- Find country in article
- Find expiration date on license
- Total bank deposit entry

**CAN'T**

- Use bus schedule
- Enter background info on SS appl
- Find intersection on street map
- Total costs on an order form

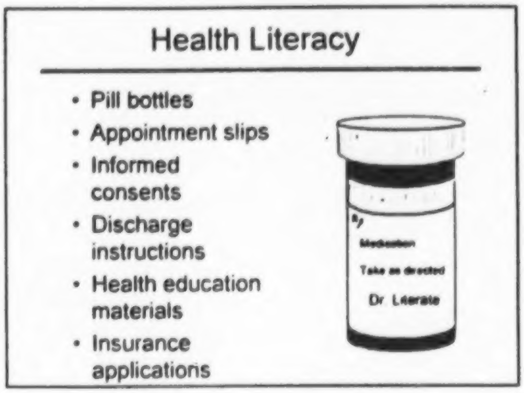
## NALS Level 2

**CAN**

- Find intersection on street map
- Locate information in newspaper article
- Determine difference in price on tickets

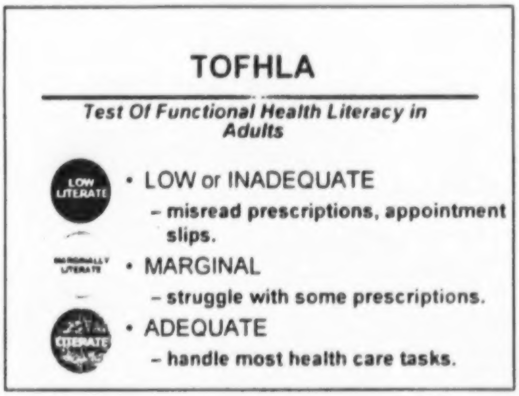
**CAN'T**

- Use bus schedule
- Identify information from bar graph
- Write a brief letter explaining error on bill



## Health Literacy

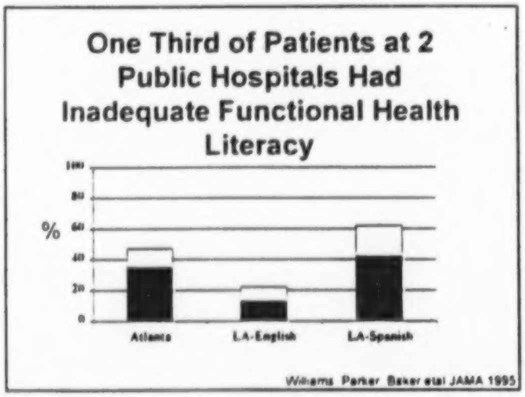
- Pill bottles
- Appointment slips
- Informed consents
- Discharge instructions
- Health education materials
- Insurance applications



## TOFHLA

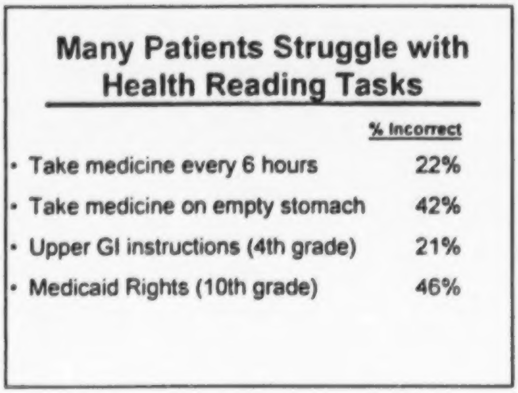
*Test Of Functional Health Literacy in Adults*

- LOW or INADEQUATE
  - misread prescriptions, appointment slips.
- MARGINAL
  - struggle with some prescriptions.
- ADEQUATE
  - handle most health care tasks.



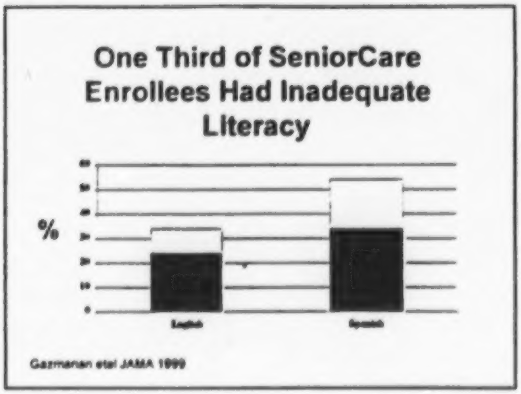
## One Third of Patients at 2 Public Hospitals Had Inadequate Functional Health Literacy

Williams Parker Baker etal JAMA 1995



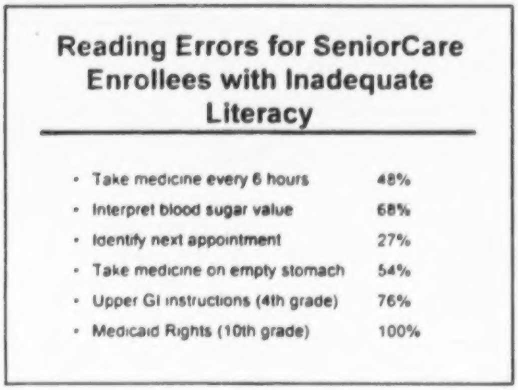
## Many Patients Struggle with Health Reading Tasks

| | % Incorrect |
|---|---|
| • Take medicine every 6 hours | 22% |
| • Take medicine on empty stomach | 42% |
| • Upper GI instructions (4th grade) | 21% |
| • Medicaid Rights (10th grade) | 46% |



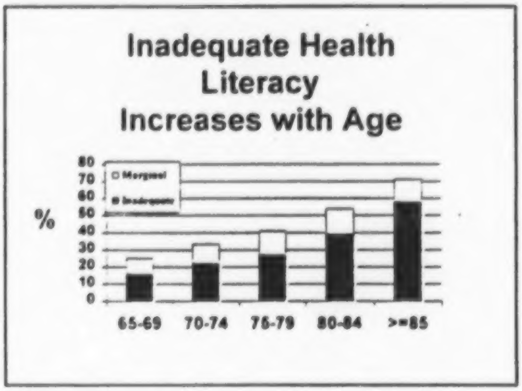
## One Third of SeniorCare Enrollees Had Inadequate Literacy

Gazmanan etal JAMA 1999

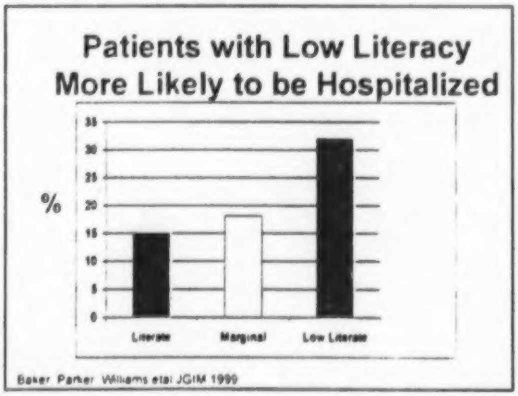


## Reading Errors for SeniorCare Enrollees with Inadequate Literacy

| | |
|---|---|
| • Take medicine every 6 hours | 48% |
| • Interpret blood sugar value | 68% |
| • Identify next appointment | 27% |
| • Take medicine on empty stomach | 54% |
| • Upper GI instructions (4th grade) | 76% |
| • Medicaid Rights (10th grade) | 100% |

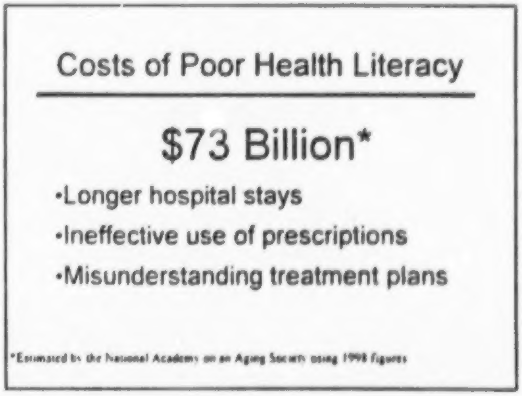


## Inadequate Health Literacy Increases with Age



## Patients with Low Literacy More Likely to be Hospitalized

Baker Parker Williams etal JGIM 1999



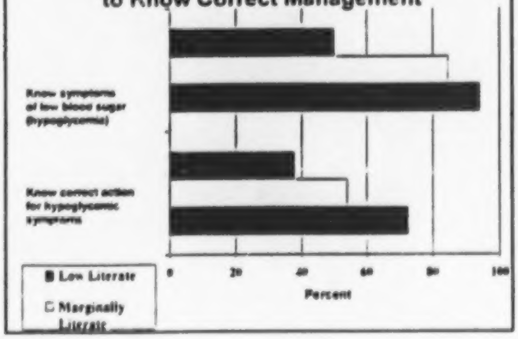
## Costs of Poor Health Literacy

**$73 Billion***

- Longer hospital stays
- Ineffective use of prescriptions
- Misunderstanding treatment plans

*Estimated by the National Academy on an Aging Society using 1998 figures

## Low Literate Diabetic Patients Less Likely to Know Correct Management



## Colorectal Cancer Screening

***Terms not understood***

- Colon
- Bowel
- Rectum
- Screening / Blood in Stool
- Polyp / Tumor
- Growth / Lesion

Davis T, et al., *Cancer Investigation*, 2000

## Prostate Cancer

Low literacy more significant predictor of late stage diagnosis than race or age.

Bennett J Clin Oncol 1998

Patients with low literacy were 69% more likely to have late stage dx.

## Compliance with Anti-HIV Meds

*Patients with low literacy*

4 times more likely to be non-compliant

Kalichman S. et al. *JGIM* 1999

## Low Literacy is Overlooked

Patients don't volunteer it

- Many patients do not recognize their inadequate literacy
- Many are ashamed of their reading problem and hide it
- Not willing to have their reading ability measured or recorded in medical record

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## Low Literacy is Overlooked

Clinicians don't ask about it

- Unaware the problem exists
- Don't know how to ask
- Don't know how to respond
- Don't want to open a Pandora's box

## Also Overlooked Because...

They don't fit the stereotype

Many NALS-1 Readers
- Are born in USA (75%)
- Are white (50%)
- Hold full or part -time job (40%)
- Finished high school (25%)

---

- Low literacy impacts quality of care and health care costs.
- Low literacy is a hidden barrier in preventive medicine.
- Low literacy impacts compliance.
- Simplifying forms/materials is necessary but won't solve the problem.

**Health ● Literacy**

A New Initiative at the AMA

Health literacy refers to the ability to read, understand, and act on health information. Approximately 90 million Americans may have problems with health literacy. National surveys have found that 21% of adults born in America cannot read the front page of a newspaper and 48% cannot read a bus schedule. Patients with low literacy are twice as likely to be hospitalized and twice as likely to report poor health. Health economists have estimated that the health literacy problem has cost health systems $73 billion annually. Older adults and persons with chronic illness have greater problems with health literacy and experience greater demands from the health care system.

Information about complex conditions or complicated treatment regimens can confuse patients regardless of their educational background or their familiarity with the medical system. However, individuals with higher literacy skills are better equipped to read the materials, navigate the health care system and access resources. When patients with low literacy skills encounter the modern health care system, they are at risk for misunderstandings, medical errors, increased hospitalizations and poorer health outcomes. A recent study found that over one-third of Medicare managed care enrollees lacked the skills to read and understand appointment slips or directions and warnings on prescription labels.

In light of these serious findings, the American Medical Association Foundation has established a Signature Program on Health Literacy and is coordinating the implementation of that program with the American Medical Association. The first product, a *Health Literacy Introductory Kit,* is a CME self-study program aimed at raising physician's awareness about the prevalence of low health literacy and how it may directly affect their relationship with their patients. The kit includes a video with vignettes illustrating the range of persons affected by this issue and the problems they experience in the medical encounter. The kit also contains the *AMA Council of Scientific Affairs Report on Health Literacy* , Fact Sheets on Health Literacy, a Discussion Guide with a physician feedback survey and a questionnaire for CME credit. The materials in the kit can be used for self-study or for leading a discussion about health literacy with colleagues, office staff, hospital staff, medical students and other health professionals. For information about future activities of this initiative or to order the *Health Literacy Introductory Kit* you may contact Joanne G. Schwartzberg, MD at 312-464-5355, or e-mail at Joanne_Schwartzberg@ama-assn.org.

AMA Foundation
AMERICAN MEDICAL ASSOCIATION FOUNDATION

Health Literacy

# Health Literacy Feedback Survey

## *The AMA Foundation needs your help....*

Health literacy refers to the ability to read, understand, and act on health care information. Approximately 90 million American may have difficulty reading and understanding health care information. Join the American Medical Association Foundation and the American Medical Association as we study the effects of low health literacy and implement programs to help physicians care for their patients/clients who may suffer from this problem.

Since the AMA Foundation began the program on health literacy one year ago, we have received many comments from practicing health care and literacy professionals about what they have tried in their encounters to improve communication with patients/clients with low health literacy. Please take a couple of minutes to respond to the following survey. Your responses and insights will assist us in guiding future activities and research on the issue of health literacy.

We would like to know how often these techniques are used. Please think back on the patient/client encounters you had in the last week when responding to the following questions.

**Techniques to improve patient comprehension that I have used in the last week:** *(Please check your answers)*

| | Never | Rarely | Occassionally | Most of the time | Always | Effective? | |
|---|---|---|---|---|---|---|---|
| | | | | | | Yes | No |
| 1. Asking patients/clients to repeat information, "teach back" technique | | | | | | | |
| 2. Speaking more slowly | | | | | | | |
| 3. Presenting 2 or 3 concepts at a time and checking for understanding | | | | | | | |
| 4. Asking patient/client how they will follow instructions at home | | | | | | | |
| 5. Using simple language (avoid technical jargon) | | | | | | | |
| 6. Reading aloud instructions | | | | | | | |
| 7. Handing out printed materials to patients/clients | | | | | | | |
| 8. Underlining key points in patient/client information handout | | | | | | | |
| 9. Writing out instruction | | | | | | | |
| 10. Drawing pictures | | | | | | | |

*(Over)*

|  | Never | Rarely | Occassionally | Most of the time | Always | Effective? |  |
|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  | Yes | No |
| 11. Using models to explain |  |  |  |  |  |  |  |
| 12. Follow-up with office staff or assistants to review instructions |  |  |  |  |  |  |  |
| 13. Follow-up with telephone call to check understanding and compliance |  |  |  |  |  |  |  |
| 14. Asking if patient/client would like family member to be in the discussion |  |  |  |  |  |  |  |

15. Other____________________________________________________________

As you try new techniques in your practice, please share promising approaches so that we can all learn ways to better serve our patients. Please send this survey and comments to Joanne G. Schwartzberg, MD, at 515 North State Street, Chicago, IL 60610. E-mail address: joanne_schwartzberg@ama-assn.org. Fax: (312) 464-5841

Name ________________________________________
Address: ________________________________________

Phone: ________________________________________
E-mail: ________________________________________

# Appendix D – Materials
# Stephen Reder and David Morgan's Presentation

*Web sites:*
*Portland State University Institute on Aging –*
***http://www.upa.pdx.edu/IOA/;***
*PSU Department of Applied Linguistics –*
***http://www-adm.pdx.edu/user/ling/index.html***

# Literacy, Age and Learning

Stephen Reder, Ph.D., and David Morgan, Ph.D.
Portland State University

This presentation considers national data that show sharp, progressive age-related declines in assessed literacy proficiency, beginning in midlife around age 45. These age-related declines in literacy may reflect developmental changes over the life course, with serious potential ramifications for the elderly. The observed decline in proficiency may reflect reduced capacities to understand health information, effectively access and utilize health services, and so forth. Improving our understanding of what this decline entails – particularly unpacking the many potential cognitive and social components of such age-related changes – can help us to develop effective compensatory interventions for maintaining the health literacy of the elderly at suitably high levels.

An important first step in better understanding the age-related decline in literacy is to disentangle the apparent effects of age from confounding influences. Variables reflecting educational attainment, employment status, physical problems and disabilities are themselves correlated with age and may be confounding the relationship we observe between age on literacy in cross-sectional data. The presentation will examine these relationships more closely. As we attempt to remove the confounding effects of other variables, the age-related decline in functional literacy remains. Though further research is needed to confirm this developmental trend, it appears quite likely that literacy abilities do progressively decline after midlife.

These age-based declines are especially important because they parallel the basic pattern found in laboratory studies on age differences in cognitive capacity. If this is indeed a developmental difference, then it means that older adults are losing cognitive capacity at the same time that they are experiencing greater health care challenges. These challenges will be most problematic when older adults have to deal with information processing demands that are complex and/or unfamiliar. In the health arena, this points to potential problems in situations such as dealing with complex medication regimens, navigating the health care system, and making decisions about treatment options. The next step in our research program to determine whether the age-based declines that occur in both this national survey and in laboratory work on cognitive capacity truly do have an impact on older adults' health care. If so, then we need to develop and assess supportive interventions to assist older adults with situations that are cognitively demanding.

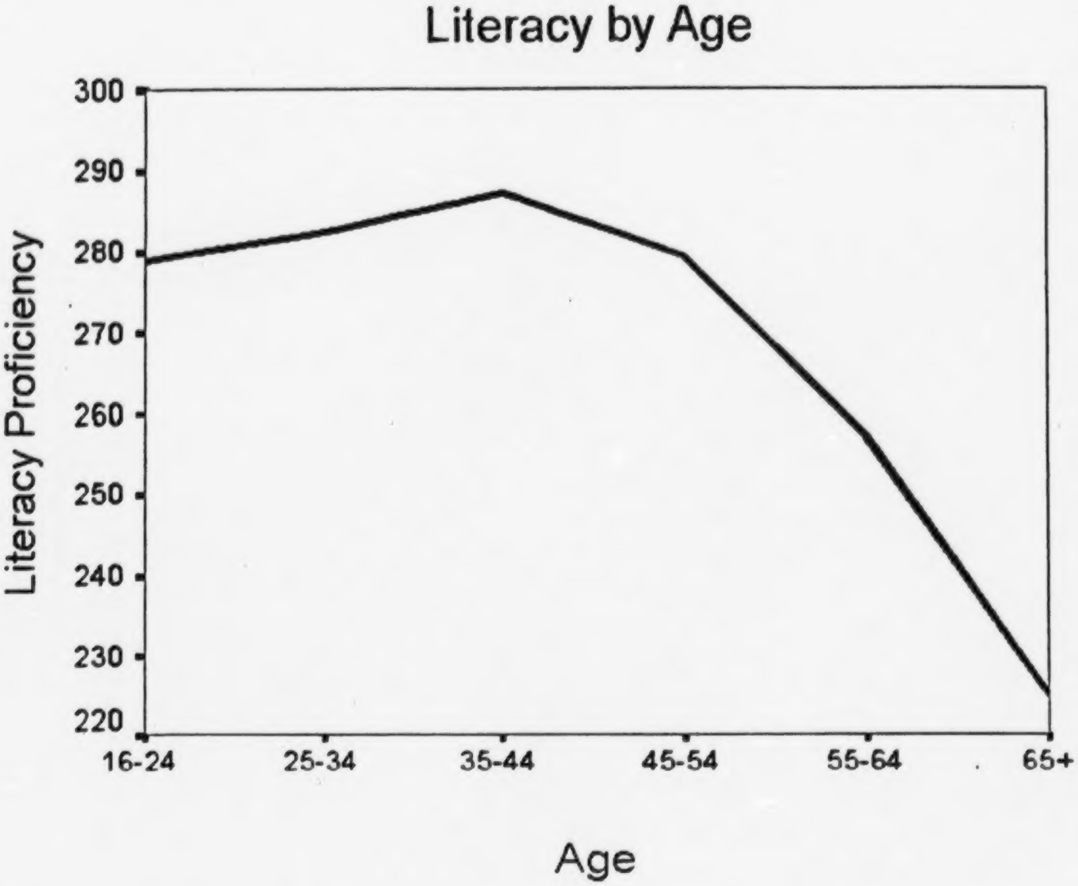
# *Literacy, Age and Learning*

Stephen Reder, Ph.D. & David Morgan, Ph.D.
Portland State University

Health Literacy Symposium
Washington D.C., August 1-2, 2001

# Literacy & Health Literacy

- Related but distinct concepts
- Literacy influences health literacy
- Literacy proficiency to us is a continuous rather than a binary or categorical capability
- We'll be looking at data from the NALS
- NALS measured literacy on 0-500 point scales (prose, document, quantitative)
- Conducted as part of large national survey


Literacy by Age
300
290
280
270
260
250
240
230
220
Literacy Proficiency
16-24
25-34
35-44
45-54
55-64
65+
Age

## Reasons to Be Cautious With Cross-Sectional Age Data

- **Well known problems of confounding developmental, cohort and period differences**
- **Many variables correlated with age may confound the observed relationship between literacy and age**
- **Overall levels of *education* are lower in the elderly, possibly confounding the effects of age and education**
- **"Use it or lose it": the elderly tend to be less employed, possibly confounding the effects of *employment* and age**
- **The elderly tend to have more physical disabilities, possibly confounding the effects of *disabilities* and age**

## Summary of Age & Literacy Data

- Substantial decline in literacy with age
- Decline cuts across diverse social, economic & educational groups
- Although some of the decline is due to other variables such as education, employment and disabilities, their confounding effects are weak in relation to the strong & robust effects of age
- Longitudinal research will clarify the nature of this decline and its relationship to health literacy

# Nature of Cognitive Losses in Aging

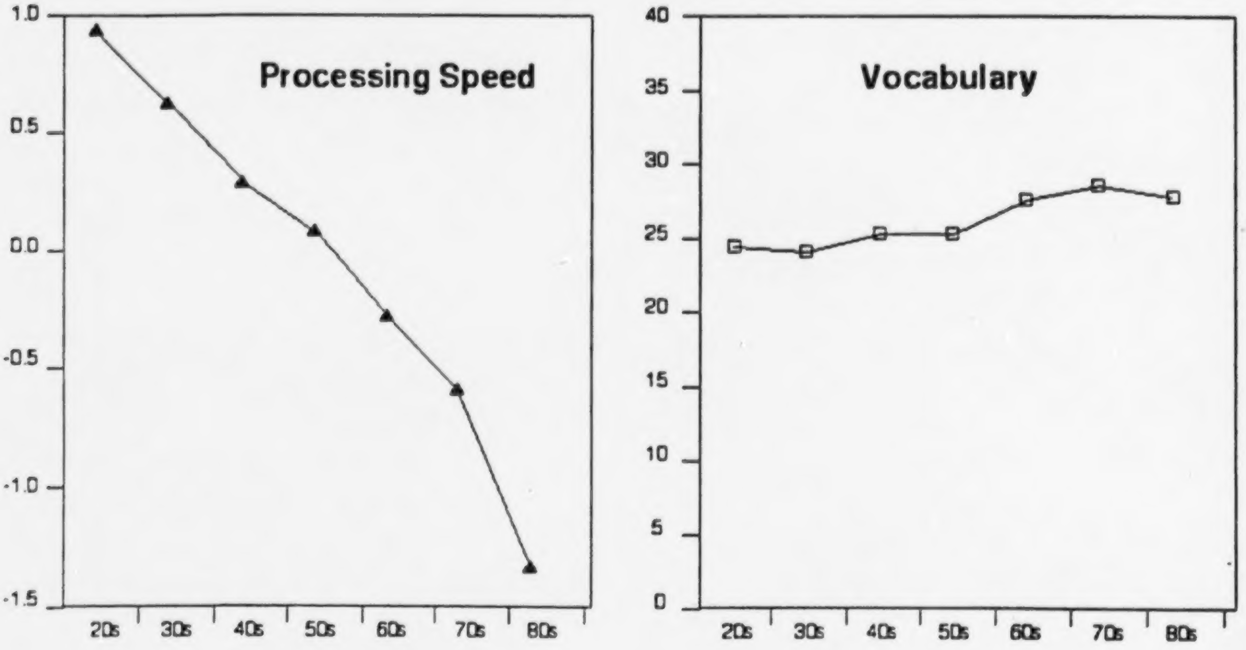
**Crystalized intelligence:**

- Uses familiar procedures and familiar data

**Fluid intelligence:**

- Uses unfamiliar procedures or unfamiliar data

Age Differences in Fluid Intelligence (Processing Speed) and Crystallized Intelligence (Vocabulary)*



*Based on Denise C. Park et al., 1997. Mediators of long-term memory performance across the life span. Psychology and Aging, 11, 621-637.

# What Makes a Difference?

Limits on the Acquisition of Information

- Sensory losses
- Distractions in the environment

Limits on Processing of Information that is Acquired

- Complex information
- Unfamiliar information
- Large amounts of information
- Presence of distracting or irrelevant information
- Time pressure

Limits on Use of Information that is Processed

- Complex tasks
- Unfamiliar tasks

# What Helps?

Successfully Acquiring Information

- An environment that highlights relevant information
- An environment that minimizes distractions
- Support for retaining information (e.g., writing things down)

Successfully Processing Information that is Acquired

- Simplifying complex information
- Clarifying complex information through conceptual frameworks
- Linking new types of information to familiar knowledge
- Breaking information into managable "chunks"
- Minimizing distracting or irrelevant information
- Providing more time to deal with information

# What Helps? (cont.)

Successfully Using Information that is Processed

- Simplifying complex tasks
- Clarifying complex tasks through conceptual frameworks
- Linking new types of tasks to things that are already familiar

In General

- *Collaboration* with others who assist in acquiring, processing, and using information

# Where Do We Go From Here?

NALS uses tasks that match real-world challenges.

Imagine a "Health Hiteracy" NALS, with items on:

- Interpreting medication instructions
- Managing regimens for multiple medications
- Making choices among different health care plans
- Filling out forms for health care claims and reimbursements
- Map use and "way finding" in large health care complexes
- "System navigation" in seeking diagnosis and treatment

This would help us define and assess health literacy based on ***functional capacity***.

# Research Program

Do age differences in NALS and laboratory measures of cognitive capacity cross-validate?

Do NALS and laboratory measures of cognitive capacity predict real-world limitations?

Can we develop strategies that help older people improve their scores on NALS?

Do strategies that improve scores on NALS also improve real-world functioning?

# Appendix D – Materials
# Helen Osborne's Presentation

*Web site:*
*Health Literacy Consulting – **http://www.healthliteracy.com***

# Working Together to Improve Health Communication with Older Adults

## Health Literacy Symposium
## August 1, 2001

Helen Osborne, M.Ed., OTR/L
Health Literacy Consulting, 31 Highland St., Natick, MA 01760
Phone: 508-653-1199 • Fax: 508-650-9492
Helen@healthliteracy.com • www.healthliteracy.com

## Working Together to Improve Health Communication with Older Adults: Strategies for Literacy Specialists and Health Professionals

### Learn about your community resources

- Healthcare facilities, including hospitals and clinics
- Local literacy programs, including community colleges and adult education programs
- Public libraries
- Community initiatives
-
-

### Introduce yourself

- Visit other facilities
- Find out the scope of each other's practice
- Talk candidly about what you can and cannot offer one another
-
-

### Share your expertise

- Informally, on a one-to-one basis
- Formally, in a structured meeting
- Exchange written information about your services
-
-

### Collaborate on specific projects

- Learn from each other ways to improve communication
- Develop teaching tools together
- Test materials for understandability
- Submit a grant proposal together
-
-

### Let others know the value of working together

- Present at an in-service training session
- Co-author an article for your local paper
- Speak at a professional conference
-
-

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Helen@healthliteracy.com • www.healthliteracy.com

## Working Together to Improve Health Communication with Older Adults: Case Discussion

Miss A. is an 67-year old woman in your ESL class. She has been in the United States for two years, and has limited ability to read or write in English. Miss A has had a persistent cough for the past three months. She confides to you that she knows she is ill and needs to see a doctor.

Miss A. does not know how to find a medical clinic that will treat her. She worries that she will not be able to get the care she needs because of her limited English skills.

### Concerns:

From your perspective as a literacy specialist, what communication skills does Miss A. need to access appropriate medical care?

From your perspective as a health professional, what communication skills does Miss A. need to access appropriate medical care?

### Working Separately:

As a literacy specialist, realistically how can you help?

As a health professional, realistically how can you help?

### Working Together:

Ideally, how can literacy specialists and health professionals work together to help Miss A. get the treatment and care she needs?

## Working Together to Improve Health Communication with Older Adults: Case Discussion

You work as a health professional in a busy community hospital. Recently, many older patients have fallen when they try to get out of bed by themselves.

You want to alert patients and their families about ways they can help prevent these accidental falls. You want to inform them about: common reasons why patients fall, specific ways they can help, and options the staff has to prevent falls - including the use of restraints.

### Concerns:

From your perspective as a literacy specialist, what problems do you foresee communicating this information?

From your perspective as a health professional, what problems do you foresee communicating this information?

### Working Separately:

As a literacy specialist, realistically how can you help?

As a health professional, realistically how can you help?

### Working Together:

Ideally, how can literacy specialists and health professionals work together to reduce accidental falls in the hospital?

## Working Together to Improve Health Communication with Older Adults: Case Discussion

The senior center in your community has invited your organization to participate in a health fair for older adults. You want to use this opportunity as a way to raise awareness about health literacy, highlighting the need for understandable medical information.

### Concerns:

From your perspective as a literacy specialist, what do you want the community to know about health literacy?

From your perspective as a health professional, what do you want the community to know about health literacy?

### Working Separately:

As a literacy specialist, realistically how can you get this message across?

As a health professional, realistically how can you get this message across?

### Working Together:

Ideally, how can literacy specialists and health professionals work together to improve awareness about health literacy?

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by Helen Osborne, MEd, OTR/L, President, Health Literacy Consulting

# Mind What You Say...

## Speaking With and Listening to Older Adults

**Verbal communication takes many forms. In healthcare settings, it could be a standardized interview or a formal patient teaching session. It could also involve giving appointment instructions or directions to other facilities. But whatever form it takes, it's imperative for healthcare professionals to make sure all their patients understand what's being said. When the patient is an older adult, the problems associated with hearing and being heard can be especially acute.**

For patients to fully participate in their own care, they need to be able to understand both formal and informal communication. This can be a challenge at times, especially for older adults. As people age they may experience physical, cognitive, or sensory changes that affect how they speak, listen, or follow directions. They may be on medication that affects their concentration and memory. Older adults may also have concerns or fears that get in the way of their ability to understand.

Mrs. Smith, for example, is an 84-year-old woman who lives alone. She comes to her appointment complaining of shortness of breath. To make an accurate diagnosis, the nurse practitioner listens to Mrs. Smith's lungs and orders some follow-up tests. The nurse asks Mrs. Smith to go to the 7th floor to have her blood drawn, to go to the 2nd floor for a chest x-ray, and to return to her office before going to the pharmacy. Mrs. Smith cheerfully agrees. But, as the nurse later learns, Mrs. Smith leaves the facility soon after her blood is drawn. While there may be many reasons why she does not follow through, a likely reason is that Mrs. Smith did not understand or could not remember all of the nurse's instructions.

Health professionals have the responsibility to communicate in ways older adults can understand. Kathy Lyman, MS, RNC, is an adult and geriatric nurse practitioner at the Division

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of Gerontology at the Beth Israel Deaconess Medical Center. She says that health professionals have a unique perspective that they should take advantage of. "Health professionals know the patient and know their limitations," she says. Lyman offers some helpful suggestions for communication strategies that health professionals can use when they speak with and listen to older adults.

**Allow Sufficient Time**

As people age, their response times slow. Allow sufficient time for older adults to process and respond, especially when discussing information that is unfamiliar or complex.

**Identify the Patient's Priorities**

Find out what is on the patient's mind and address those concerns first. Ask patients about what is new since you saw them last. You might learn of a medical concern you were unaware of. "If I don't first take care of what's on their mind," says Lyman, "it will be a wasted visit."

**Direct the Conversation**

There may be times when patients persist in talking about matters unrelated to the medical visit. Acknowledge that you hear their concerns and then direct them back to the matters at hand. One way to do this is to say, "That must be quite a worry for you. For now, though, let's talk about how you manage your medications at home."

**Give Directions One Step at a Time**

When giving directions, present information one step at a time. Allow patients sufficient time to process each step before going on to the next. Offer to write down the directions as well, providing a written reminder of what you said.

**Assume Responsibility to Remember**

Most everyone, regardless of age, forgets information. Take notes while you talk with patients, explaining that these notes are for your benefit as much as the patient's. Offer the patient a copy to take home, and keep one for yourself as well. Refer to these notes before the patient's next visit so you can follow up on what was said and done the last time you saw the patient.

**Offer Additional Help as Needed**

Sometimes patients need more than verbal instructions. If you are concerned that Mrs. Smith may not remember to go to x-ray, for example, take the time to find someone who can escort her. Appreciate that the time you spend arranging for additional help may make a big difference in a patient's care. "Don't be quick to judge that a task is not worth your effort," says Lyman.

**Respond to Repetitive Information as if It Is New**

Whether due to dementia, anxiety, or simply conversational style, some people tend to say the same thing over and over again. Try not to criticize when people repeat themselves. It may make them feel angry, frustrated, or even agitated when they are frequently corrected. After you hear information a second time, simply spend less time talking about it than you did when the information was new.

**Confirm That You Understand Each Other**

Make it a habit to repeat back, in your own words, what you hear patients say. You might, for example, say, "When you told me you had a small appetite, I understood that you were only eating a sandwich at dinner time. Is that correct?" In turn, ask patients to tell you what they hear. Assume responsibility for effective communication, inviting patients to let you know when they don't understand.

**Find Practice Settings That Match Your Communication Style**

Health professionals are not equally skilled at speaking with and listening to older adults. Find a practice setting that matches your communication style, seeking situations in which you are comfortable and effective and in which patients have let you know that you are doing a good job. ☐

## How to Learn More

Katherine Lyman, MS, RNC, is an adult and geriatric nurse practitioner at the Division of Gerontology at Beth Israel Deaconess Medical Center in Boston. You can reach her by E-mail at klyman@caregroup.harvard.edu or by phone at (617) 667-4580.

Helen Osborne gives workshops on communicating with older adults. To learn more, contact her by e-mail at: helen@healthliteracy.com or visit her Health Literacy Consulting Web site at www.healthliteracy.com

**Publications**

Kick, E (Sept. 1989). Patient teaching for elders. *Nursing Clinics of North America*, Vol. 24(3), 681-687.

National Literacy and Health Program, Canadian Public Health Association (1998). *Working with Low-literacy Seniors: Practical Strategies for Health Providers*. To order, contact the Health Resources Centre by telephone at (613) 725-3769, ext. 190, or by e-mail at hrc/cds@cpha.ca.

Pearson, M, Wessman, J (1996). Gerogogy. *Home Healthcare Nurse*, Vol. 14, No. 8, 632-636.

Some of the information in this article is adapted with permission from the book, *Overcoming Communication Barriers in Patient Education* by Helen Osborne, Aspen Publishers, Inc., Gaithersburg, MD. (2000). This book offers practical strategies healthcare professionals can use for teaching patients who have poor reading skills, are older, have visual or hearing impairments, speak little or no English, or come from other cultures. To order a copy, contact Aspen Publishers, Inc. through their Web site: www.aspenpublishers.com or by phone: (800) 638-8437.

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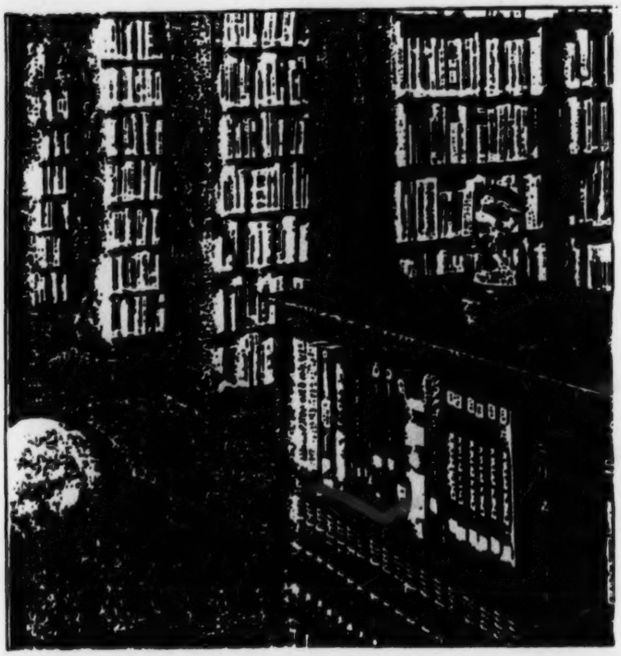
# in other words...

by Helen Osborne, MEd, OTR/L, President, Health Literacy Consulting



# When You Need to Know..

## *Literacy resources for health professionals*

**In an ideal clinical situation, health providers and patients always understand one another. But in reality this is not necessarily the case. Patients may lack skill they need to understand unfamiliar medical words an complex healthcare concepts. Part of a healthcare professional's responsibility is to help them understand. But where can you get the help you need to do that?**

Through the years, I have learned a lot from working with teachers and literacy specialists about how to communicate clearly and simply. We have shared knowledge about how people learn and applied it to the presentation of healthcare content people need to know. Together, we have come up with understandable ways to communicate. This month's column focuses on literacy-related resources that health providers can use to communicate in ways that help patients understand

### NIFL

The National Institute for Literacy (NIFL) is an independent federal organization that is leading the effort toward a fully literate nation in the 21st century According to NIFL, at least 40 million adults in America need to improve their literacy skills. This means that people need adequate reading, writing, and computational (math) skills in order to fully function at home, at work, and in the community. To meet this goal, NIFL offers many literacy resources. Three of these (described below) have information specific to health

**LINCS** is a literacy information and communication system. It offers an online collection of adult education and literacy resources. LINCS includes online discussion groups, special collections of resources, literacy-related research and statistics, policy and legislation information, a calendar of events, grant and funding sources, and links to other literacy databases. The LINCS Web site is designed to be easy to use. It includes search capabilities, archives, "hot" sites, and a personalized feature called "My LINCS" that notifies you when there is new information in a subject area you are interested in. To access LINCS, go to www.nifl.gov/lincs.

**LINCS Health & Literacy Special Collection** is an online resource for teachers, students, health educators, and anyone interested in teaching health to people with limited literacy skills. Through this online resource y can find information about the link between literacy and health status, resources to provide basic health inf mation in simple language, health curricula for literacy classes, and links organizations dedicated to health an literacy education. To access the Heal & Literacy Special Collection, go to www.nifl.gov/lincs and click on "collec tions."

**NIFL-Health** is an online discussi group (or "listserv") about health liter acy. Subscribers can participate in NIFL-Health by asking and answering questions or simply reading what oth have to say. There are currently more than 500 NIFL-Health subscribers. Th include health professionals, literacy specialists, students, teachers, and researchers from around the world. I moderate NIFL-Health with a literacy specialist.

Through subscribing to this servic

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you can keep up-to-date on the topic of health literacy by discussing issues, sharing resources, and asking questions of experts. You can also access an archive of all the discussions and search them by topic, author, date, or thread. Topics vary widely. There have been practical discussions about how much white space to include in written materials or where to find easy-to-read and translated health information. There have also been philosophic discussions, including one about the value of assessing patients' literacy skills. At times, there are also guest discussion leaders. Anne Fadiman was a guest who answered questions about her award-winning book, *The Spirit Catches You and You Fall Down*. An adult learner was another guest. He shared what it feels like to be a patient who cannot understand written health information.

NIFL-Health is just one of several online discussion groups sponsored by NIFL. Other groups include: Equipped for the Future, English as a Second Language, Family Literacy, Focus on Basics, Homelessness & Literacy, Learning Disabilities, Poverty, Race, & Literacy, Technology & Literacy, Women & Literacy, and Workplace Literacy. To find and subscribe to the group or groups that interest you, go to www.nifl.gov/lincs and click on "discussions."

### World Education

World Education in Boston is a non-profit organization dedicated to improving the lives of the poor through economic and social development programs. World Education manages NIFL's Health and Literacy Special Collection. It also publishes resources specific to health and literacy. These resources include the following.

**Health and Literacy Compendium,** developed by World Education in collaboration with NIFL, is an annotated bibliography of health materials appropriate for limited-literacy adults. It includes over 80 citations of print and Web-based materials. The Compendium includes health information that literacy specialists can use with students. It also includes literacy information and easy-to-read health materials that health professionals can use with patients. The Compendium contains information about

- links between health status and literacy status
- assessing and developing easy-to-read health education materials
- teaching health with literacy in mind
- teaching literacy using health content
- bibliographies and databases of easy-to-read or multilingual health information
- bibliographies and databases of connections between health and literacy

**Culture, Health, and Literacy: A Guide to Health Education Materials for Adults with Limited English Literacy Skills** is an addendum to the Compendium. It includes health materials that address issues relevant to various cultural groups as well as materials available in other languages.

The Health and Literacy Compendium and Culture, Health, and Literacy are both free and available in hard copy as well as online. To access these resources, go to www.worlded.org /us/health/lincs. Or contact Julie McKinney at World Education in Boston by phone at (617) 482-9485. The e-mail address is jmckinney@worlded.org

### The National Adult Literacy Survey (NALS)

The US Department of Education commissioned a survey in 1992 of the literacy skills of English-speaking adults in the United States. Based on more than 26,000 interviews, this survey looked at people's ability to comprehend prose (such as in newspapers and books), documents (such as maps and schedules), and quantitative (numeric) information. Results show that nearly half of the adults in the US have inadequate literacy skills. Not surprisingly, people who are older, disabled, have a poor education, or come from non-English speaking homes have an even higher percentage of difficulty. This data can help health professionals appreciate why so many patients have trouble comprehending health care information.

**Adult Literacy in America** is a detailed report about the NALS data. It not only defines literacy and describes the study, it also looks at survey data by age, level of education, race/ethnicity, disability or illness, region, sex, and the prison population. The report also looks at the connection between adult literacy skills and socioeconomic characteristics. *Adult Literacy in America* is no longer in print, but it is available online at www.ed.gov/pubs/ edpubs.html.

**Literacy of Older Adults in America** looks at NALS data specific to people 65 years and older. The report includes profiles for various subgroups of this population and examines ways that literacy affects employment, civic participation, and economic status. *Literacy of Older Adults in America* is available in print or online. To order a copy, call (800) 228-8813 or visit www.ed.gov/ pubs/edpubs.html.

**The State of Literacy in America,** also based on NALS data, provides an estimate of how many adults have low literacy in each state, county, Congressional district, and large city in the United States. This data is a powerful way to raise awareness that issues involving literacy affect all of us, no matter where we live, work, or provide healthcare. To order a copy, call (800) 228-8813, or visit www.ed.gov/pubs/ edpubs.html.

### National Library of Medicine

The National Library of Medicine, Health Literacy Bibliography is a database of journal articles about health literacy. It includes 479 health literacy citations published between January 1990 and October 1999. While the bibliography is not intended to be all inclusive, it does provide an excellent way to begin a search for information. To access the bibliography, go to: www.nlm.nih.gov/pubs/cbm/ hliteracy.html. ☐

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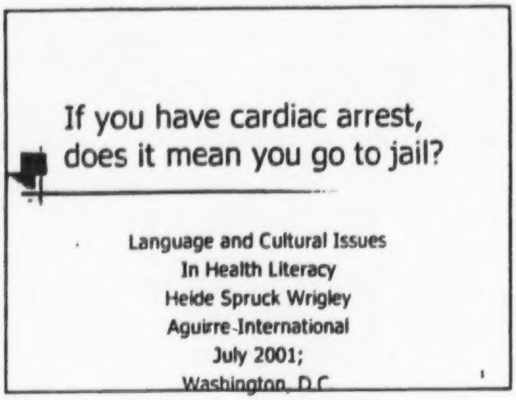
[illegible] On Call. On Call is published by Globe Specialty Products, Inc., a wholly-owned subsidiary of *The Boston Globe*.

- E. Kick, "Patient Teaching for Elders," *Nursing Clinics of North America*, Vol. 24(3), Sept 1989: 681 –687. (Includes some myths about learning by older people.)
- K. Kiefer (2001). *Health Literacy: Responding to the Need for Help*. Center for Medicare Education. (An examination of health literacy, including examples of programs designed to meet the needs of people who have difficulty reading.)
- *Literacy of Older Adults in America.* (NALS data specific to people 65 years and older.) To order a copy, call 800-228-8813, or visit www.ed.gov/pubs/edpubs.html.
- NIFL-Health. (An online discussion group about health literacy.) To subscribe, go to www.nifl.gov/lincs, click on "discussions," scroll to "health and literacy," and follow the directions to subscribe.
- H. Osborne: "In Other Words…" columns in *On Call* magazine. (A series of articles about health care communication and patient education.) Available on the Health Literacy Consulting Web site: www.healthliteracy.com
- H. Osborne (2001). *Overcoming Communication Barriers in Patient Education.* Aspen Publishers, Inc., Gaithersburg, MD. (Practical strategies to communicate with patients who have poor reading skills, are older, have visual or hearing impairments, speak little or no English, or come from other cultures.) To order, call Aspen at 800-638-8437, or visit their Web site at www.aspenpublishers.com
- *Working with Low-literacy Seniors; Practical Strategies for Health Providers.* National Literacy and Health Program, Canadian Public Health Association. 1998. (Practical strategies for plain language writing and clear verbal communication with low-literacy seniors.) To order, contact the Health Resources Centre by telephone: 613-725-3769, ext. 190, or by e-mail at: hrc/cds@cpha.ca

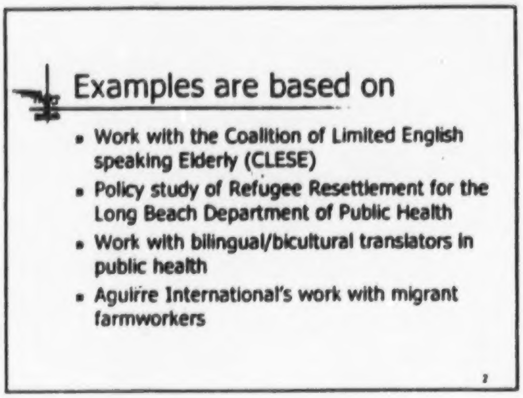
# Appendix D – Materials
# Heide Wrigley's Presentation

*Web site:*
*Aguirre International* – ***http://www.aguirreinternational.com/***



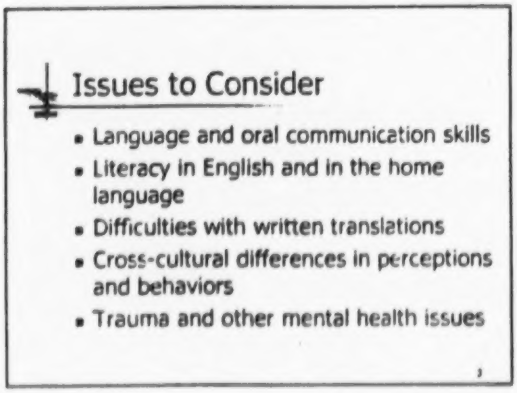
## If you have cardiac arrest, does it mean you go to jail?

Language and Cultural Issues
In Health Literacy
Heide Spruck Wrigley
Aguirre International
July 2001;
Washington, D.C.



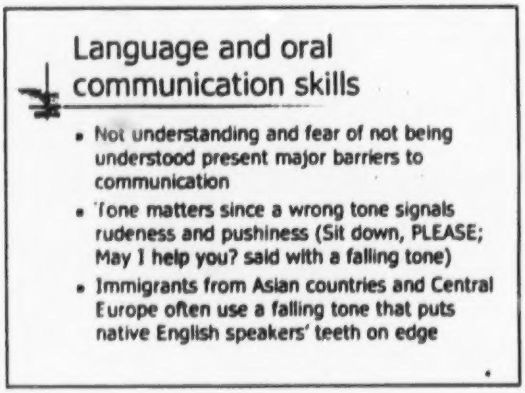
## Examples are based on

- Work with the Coalition of Limited English speaking Elderly (CLESE)
- Policy study of Refugee Resettlement for the Long Beach Department of Public Health
- Work with bilingual/bicultural translators in public health
- Aguirre International's work with migrant farmworkers



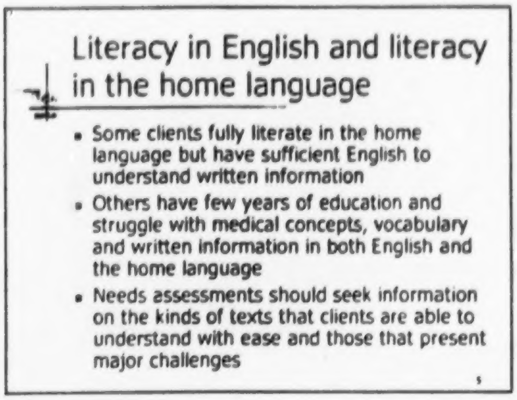
## Issues to Consider

- Language and oral communication skills
- Literacy in English and in the home language
- Difficulties with written translations
- Cross-cultural differences in perceptions and behaviors
- Trauma and other mental health issues



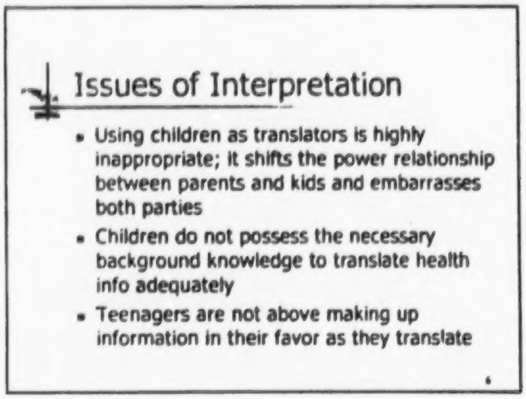
## Language and oral communication skills

- Not understanding and fear of not being understood present major barriers to communication
- Tone matters since a wrong tone signals rudeness and pushiness (Sit down, PLEASE; May I help you? said with a falling tone)
- Immigrants from Asian countries and Central Europe often use a falling tone that puts native English speakers' teeth on edge



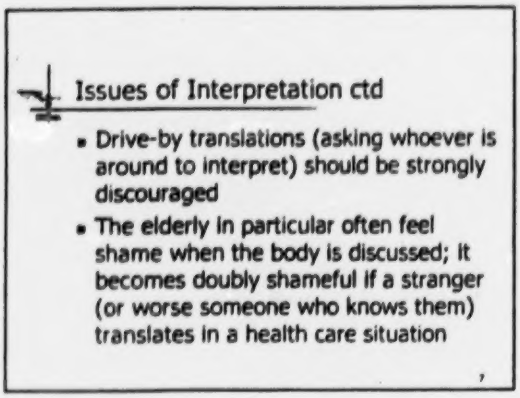
## Literacy in English and literacy in the home language

- Some clients fully literate in the home language but have sufficient English to understand written information
- Others have few years of education and struggle with medical concepts, vocabulary and written information in both English and the home language
- Needs assessments should seek information on the kinds of texts that clients are able to understand with ease and those that present major challenges



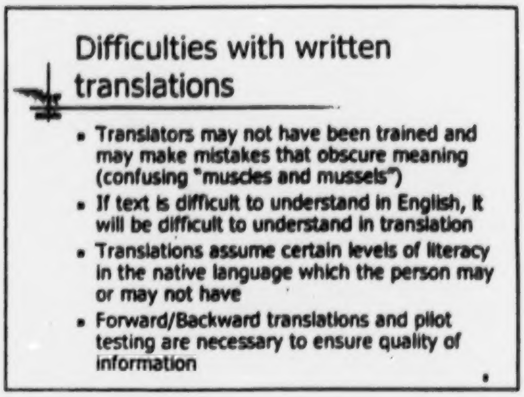
## Issues of Interpretation

- Using children as translators is highly inappropriate; it shifts the power relationship between parents and kids and embarrasses both parties
- Children do not possess the necessary background knowledge to translate health info adequately
- Teenagers are not above making up information in their favor as they translate



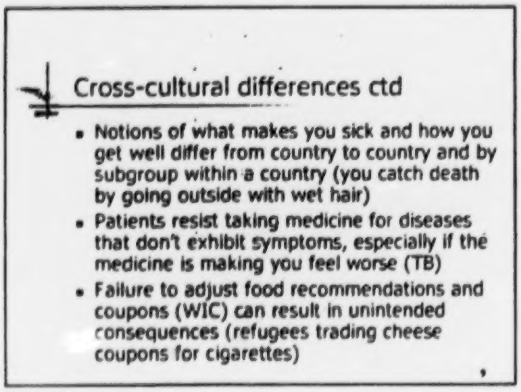
## Issues of Interpretation ctd

- Drive-by translations (asking whoever is around to interpret) should be strongly discouraged
- The elderly in particular often feel shame when the body is discussed; it becomes doubly shameful if a stranger (or worse someone who knows them) translates in a health care situation



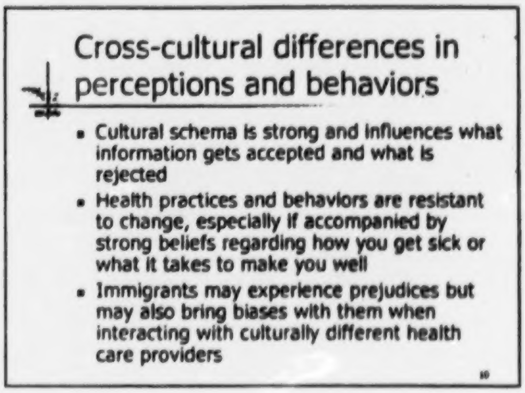
## Difficulties with written translations

- Translators may not have been trained and may make mistakes that obscure meaning (confusing "muscles and mussels")
- If text is difficult to understand in English, it will be difficult to understand in translation
- Translations assume certain levels of literacy in the native language which the person may or may not have
- Forward/Backward translations and pilot testing are necessary to ensure quality of information



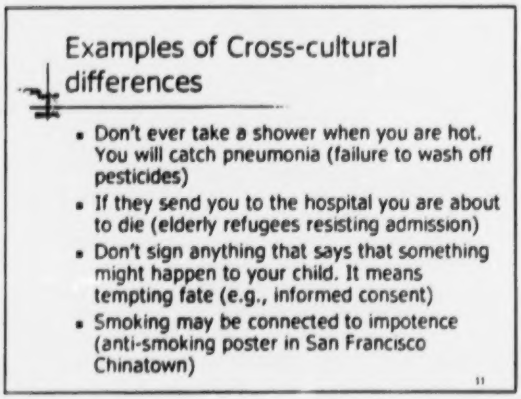
## Cross-cultural differences ctd

- Notions of what makes you sick and how you get well differ from country to country and by subgroup within a country (you catch death by going outside with wet hair)
- Patients resist taking medicine for diseases that don't exhibit symptoms, especially if the medicine is making you feel worse (TB)
- Failure to adjust food recommendations and coupons (WIC) can result in unintended consequences (refugees trading cheese coupons for cigarettes)



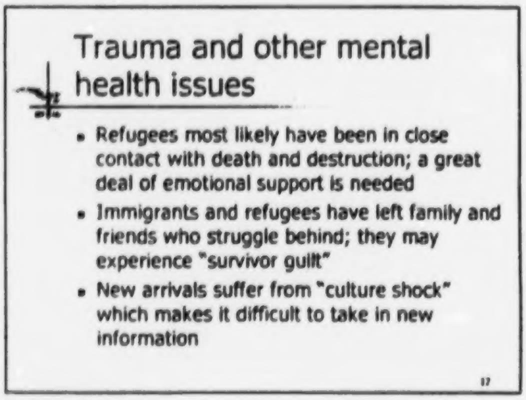
## Cross-cultural differences in perceptions and behaviors

- Cultural schema is strong and influences what information gets accepted and what is rejected
- Health practices and behaviors are resistant to change, especially if accompanied by strong beliefs regarding how you get sick or what it takes to make you well
- Immigrants may experience prejudices but may also bring biases with them when interacting with culturally different health care providers



## Examples of Cross-cultural differences

- Don't ever take a shower when you are hot. You will catch pneumonia (failure to wash off pesticides)
- If they send you to the hospital you are about to die (elderly refugees resisting admission)
- Don't sign anything that says that something might happen to your child. It means tempting fate (e.g., informed consent)
- Smoking may be connected to impotence (anti-smoking poster in San Francisco Chinatown)



## Trauma and other mental health issues

- Refugees most likely have been in close contact with death and destruction; a great deal of emotional support is needed
- Immigrants and refugees have left family and friends who struggle behind; they may experience "survivor guilt"
- New arrivals suffer from "culture shock" which makes it difficult to take in new information

## Undocumented immigrants

- They live in constant fear and often don't access the services they are entitled too
- Children may be citizens and be eligible for services while parents are not
- Public health in Texas is colloaborating with Border Patrol to help ensure health and safety of those crossing the Rio Grande

## Undocumented immigrants

- **Coyotes : A Journey Through the Secret World of America's Illegal Aliens**
by Ted Conover

## Cross-cultural differences in perceptions and behaviors ctd

- Doctors take your blood and then the hospital will sell it at the blood bank
- The medicines the doctor gives you are too strong for Asians; it is better to just take half

## Structural and Institutional Barriers

- Two tiered system as post '96 immigrants may be denied Medicaid as a state option
- Care in the home country more familiar and comfortable; care is delayed till next visit

## Structural and Institutional Barriers

- Lack of teeth in legislation makes it difficult to enforce statutes that guarantee the right to translation
- Attitude of providers gets in the way ("they gotta speak English if they want services here")
- Inadequate access to translators or "walk-by translations" where children or others are pressed into service
- Providers may know little about different groups and their health practices

## Concerns particular to elderly immigrants

- Multiple losses – friends are dying; friends and family may have been killed in civil strive or war; homes have been lost or left behind
- difficulties acerbated by health problems and other challenges of getting older (vision; hearing; short term memory loss)
- It's difficult to remember what medicine to take when. ( The prescription may be in English and the bilingual pharmacist does not provide a written translation)

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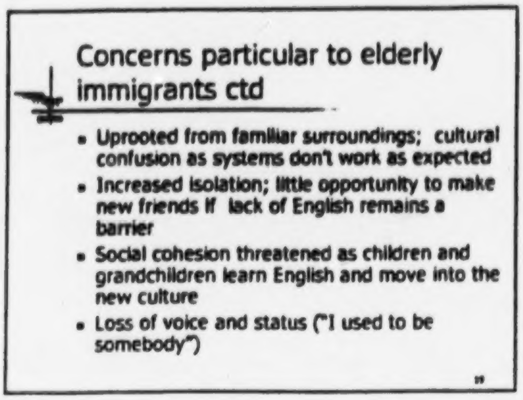
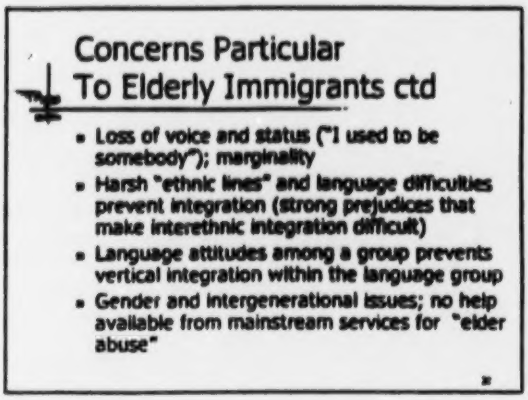


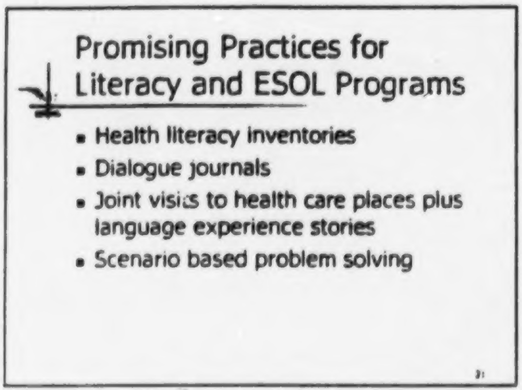
## Concerns particular to elderly immigrants ctd

- Uprooted from familiar surroundings; cultural confusion as systems don't work as expected
- Increased isolation; little opportunity to make new friends if lack of English remains a barrier
- Social cohesion threatened as children and grandchildren learn English and move into the new culture
- Loss of voice and status ("I used to be somebody")



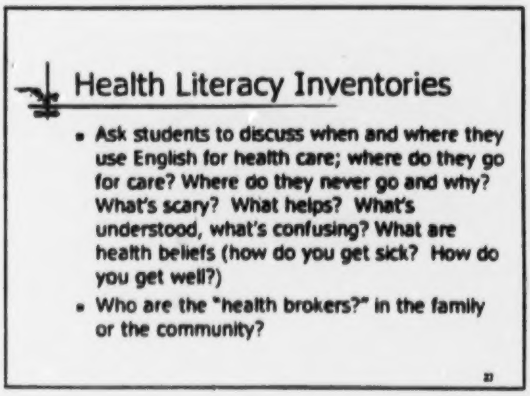
## Concerns Particular To Elderly Immigrants ctd

- Loss of voice and status ("I used to be somebody"); marginality
- Harsh "ethnic lines" and language difficulties prevent integration (strong prejudices that make interethnic integration difficult)
- Language attitudes among a group prevents vertical integration within the language group
- Gender and intergenerational issues; no help available from mainstream services for "elder abuse"



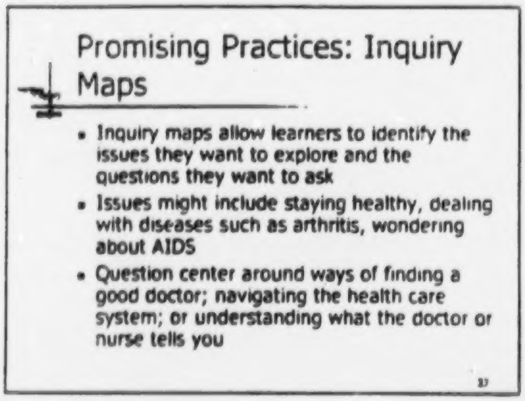
## Promising Practices for Literacy and ESOL Programs

- Health literacy inventories
- Dialogue journals
- Joint visits to health care places plus language experience stories
- Scenario based problem solving



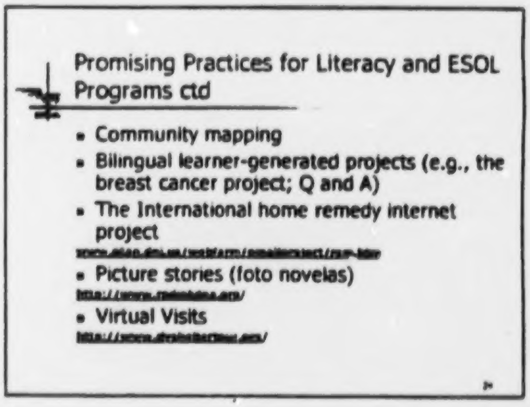
## Health Literacy Inventories

- Ask students to discuss when and where they use English for health care; where do they go for care? Where do they never go and why? What's scary? What helps? What's understood, what's confusing? What are health beliefs (how do you get sick? How do you get well?)
- Who are the "health brokers?" in the family or the community?



## Promising Practices: Inquiry Maps

- Inquiry maps allow learners to identify the issues they want to explore and the questions they want to ask
- Issues might include staying healthy, dealing with diseases such as arthritis, wondering about AIDS
- Question center around ways of finding a good doctor; navigating the health care system; or understanding what the doctor or nurse tells you



## Promising Practices for Literacy and ESOL Programs ctd

- Community mapping
- Bilingual learner-generated projects (e.g., the breast cancer project; Q and A)
- The International home remedy internet project
[illegible]
- Picture stories (foto novelas)
[illegible]
- Virtual Visits
[illegible]

## Promising Practices for Programs and Communities

- Peer health educators as outreach workers
- Advocacy to ensure availability of translators
- Guide to the health care system in multiple languages (cf. Illinois)
- Kits for managed care providers to develop cross-cultural competence

## Promising Practices for Programs ctd

- Agency self-assessments to examine the degree of "cultural competence"
- Linking ESOL teachers to a wider network of social service and health care providers
- Health fairs by ethnic neighborhoods with food, bilingual entertainment (popular theater) and art

## Favorite Books

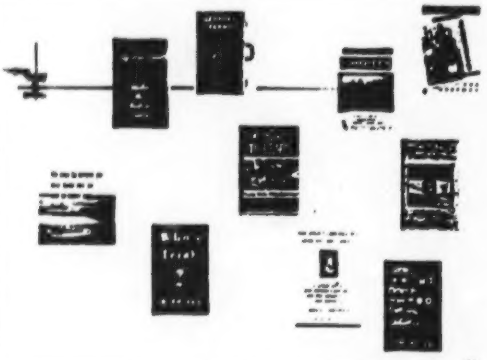
- **Caring for Patients from Different Cultures : Case Studies from American Hospitals (2nd Edition)**
  by Geri-Ann Galanti
- **The Spirit Catches You and You Fall Down A Hmong Child, Her American Doctors, and the Collision of Two Cultures**
  by Anne Fadiman
- **Who's Irish? : Stories**
  by Gish Jen
  (stories of New York Chinatown)

## Favorite Books

- **We Wish to Inform You That Tomorrow We Will be Killed With Our Families: Stories from Rwanda**
  by Philip Gourevitch
- **Lost in Translation : A Life in a New Language**
  by Eva Hoffman
- **Child of War, Woman of Peace**
  by Le Ly Hayslip, James Hayslip (Contributor), Jenny Wurts
- **Under the Feet of Jesus**
  by Helena Maria Viramontes

## Important books on women and trauma

- **Too Scared to Learn : Women, Violence, and Education**
  by Jenny Horsman
- **See also Janet Isserlis' webpage on women and violence**
- http://www.brown.edu/Departments/Swearer_Center/Literacy_Resources/screen.html
- **The Blue Room : Trauma and Testimony Among Refugee Women : A Psycho-Social Exploration**
  by Inger Agger, Mary Bille (Translator)



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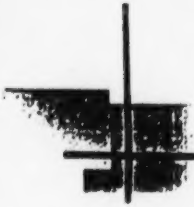
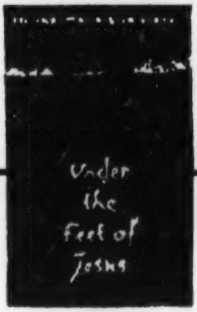
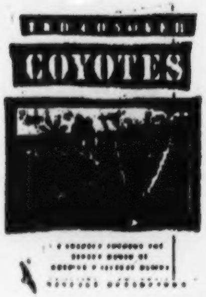
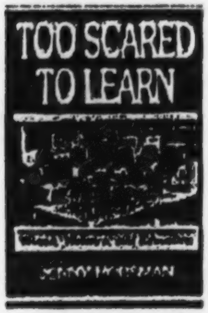



Under the Feet of Jesus

LETTERS of TRANSIT


TED CONOVER
COYOTES

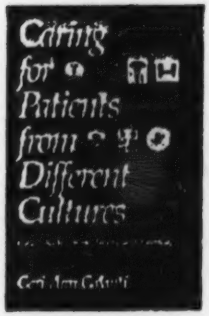
LOST IN TRANSLATION
EVA HOFFMAN


TOO SCARED TO LEARN

We wish to inform you
that tomorrow we
will be killed with
our families

Who's Irish
?
GISH JEN

THE SPIRIT CATCHES YOU
AND YOU FALL DOWN


Caring for Patients from Different Cultures
Geri-Ann Galanti

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# Appendix D – Materials
# William Hawk, Sabrina Kurtz-Rossi, Julie McKinney and Carolyn Staley's Presentation

*Web sites:*
*NIFL –* ***http://www.nifl.gov;***
*World Education --* ***http://www.worlded.org***

In addition to the materials included with this report, the presenters distributed copies of the "Health and Literacy Compendium" and "Culture, Health, and Literacy" resource guides. These guides are available online through the LINCS Health & Literacy Special Collection site at http://www.worlded.org/us/health/lincs/ They are also available on World Education's site at http://www.worlded.org/publications.htm

WORLD EDUCATION

*Announcing...*

## *The Health & Literacy Special Collection!*

**What is it?**

It is a Web site for teachers, students, health educators, or anyone interested in teaching health to adults with limited literacy skills. The site can direct you to free or low-cost materials, or allow you to download them directly. From this site, you can find:

- Health curricula for literacy or ESOL classes
- Guides for incorporating health into literacy education
- Health brochures in plain English, or languages other than English
- Information about the link between literacy and health status
- Links to organizations dedicated to health and literacy education

**Where is it from?**

The site is maintained by World Education in Boston, with support from the National Institute for Literacy (NIFL), and its LINCS project. LINCS is a national effort to provide Web-based access to information for adult literacy practitioners. The Health & Literacy Special Collection is one of ten collections of resources relating to specific content areas within literacy education.

**How do I find it?**

**Go to: http://www.worlded.org/us/health/lincs [illegible]**

**Or go to: http://www.nifl.gov/lincs and click on "Collec[illegible]**
**"Health & Literacy" [illegible]**

**Can I give input?**

Yes! Yes! Yes! We are looking for input from practitioners in the field, so that we can make this most helpful to you. Please contact us with your feedback about the site, needs for health materials that you can't find, or recommendations for exceptional health-related materials that we can add to the site.

Contact: **Julie McKinney, Coordinator, Health & Literacy Special Collection**
**World Education (617) 482-9485 jmckinney@worlded.org**

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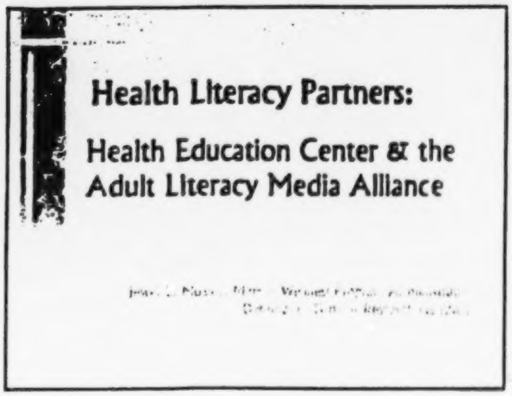
# Appendix D – Materials
# Dynishal Gross and Jewel Mosley's Presentation

*Web sites:*
*ALMA* – **http://www.tv411.org;**
*HEC – N/A*



## Health Literacy Partners:

## Health Education Center & the Adult Literacy Media Alliance

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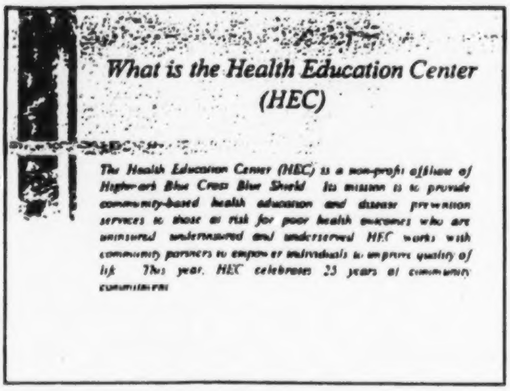
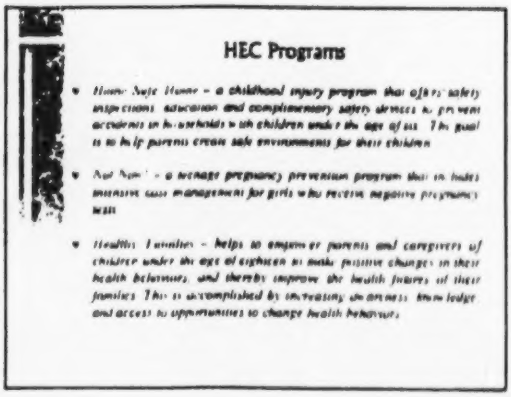


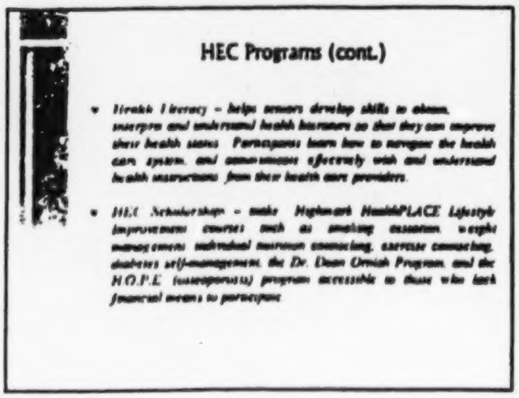
## *What is the Health Education Center (HEC)*

*The Health Education Center (HEC) is a non-profit affiliate of Highmark Blue Cross Blue Shield. Its mission is to provide community-based health education and disease prevention services to those at risk for poor health outcomes who are uninsured, underinsured and underserved. HEC works with community partners to empower individuals to improve quality of life. This year, HEC celebrates 25 years of community commitment.*



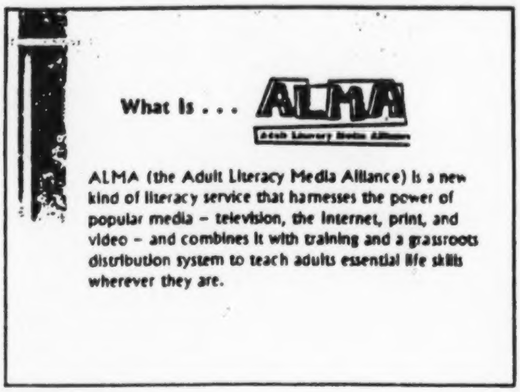
## HEC Programs

- *Home Safe Home – a childhood injury program that offers safety inspections, education and complimentary safety devices to prevent accidents in households with children under the age of six. The goal is to help parents create safe environments for their children.*
- *Not Now! – a teenage pregnancy prevention program that includes intensive case management for girls who receive negative pregnancy tests.*
- *Healthy Families – helps to empower parents and caregivers of children under the age of eighteen to make positive changes in their health behaviors, and thereby improve the health futures of their families. This is accomplished by increasing awareness, knowledge and access to opportunities to change health behaviors.*



## HEC Programs (cont.)

- *Health Literacy – helps seniors develop skills to obtain, interpret and understand health literature so that they can improve their health status. Participants learn how to navigate the health care system, and communicate effectively with and understand health instructions from their health care providers.*
- *HEC Scholarships – make Highmark HealthPLACE Lifestyle Improvement courses such as smoking cessation, weight management, individual nutrition counseling, exercise counseling, diabetes self-management, the Dr. Dean Ornish Program, and the H.O.P.E. (osteoporosis) program accessible to those who lack financial means to participate.*



## What Is . . . ALMA

Adult Literacy Media Alliance

ALMA (the Adult Literacy Media Alliance) is a new kind of literacy service that harnesses the power of popular media – television, the Internet, print, and video – and combines it with training and a grassroots distribution system to teach adults essential life skills wherever they are.

TV 411

### The Show

TV411 is Emmy award-winning television show that embeds literacy learning in popular television formats. The primary themes of the show, identified through research with adult learners are money, parenting, employment & health. To date 20 episodes have been produced.

### The Magazine

TV411: In Print is an accompanying 12-page, magazine-style workbook which explores in further depth many of the learning concepts presented in the show. TV411 In Print deepens the instructional impact of the program by providing opportunities to practice the skills seen in the show.

### The Website

TV411 Online (available in September) features such tools as interactive lessons, a writing gallery, and activities around the themes of money, parenting, people, and health. In addition, the site has a registered user's portfolio to store learners' work, along with an email Q&A feature to provide users with additional, personalized support.

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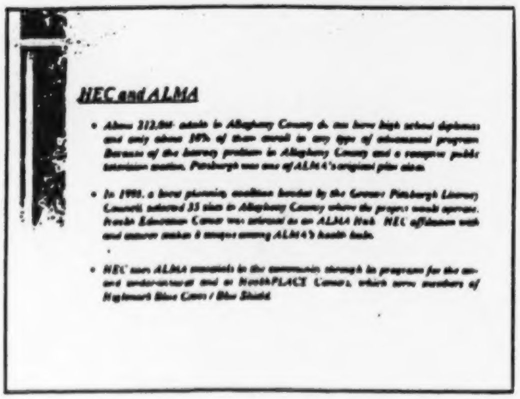
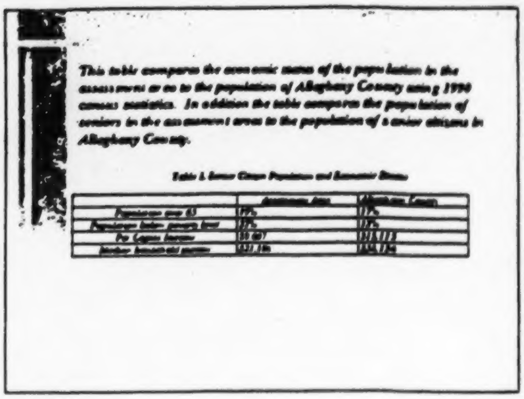


## HEC and ALMA

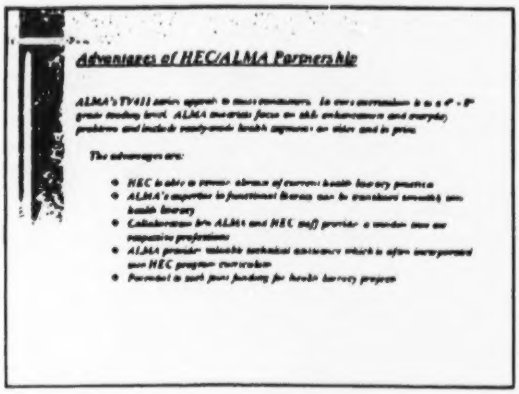
- About 212,000 adults in Allegheny County do not have high school diplomas and only about 10% of them enroll in any type of educational program. Because of the literacy problem in Allegheny County and a receptive public television station, Pittsburgh was one of ALMA's original pilot sites.
- In 1995, a local planning coalition headed by the Greater Pittsburgh Literacy Council selected 35 sites in Allegheny County where the project would operate. Health Education Center was selected as an ALMA Hub. HEC affiliation with and interest makes it unique among ALMA's health hubs.
- HEC uses ALMA materials in the community through its programs for the un- and underinsured and at HealthPLACE Centers, which serve members of Highmark Blue Cross / Blue Shield.



This table compares the economic status of the population in the assessment area to the population of Allegheny County using 1990 census statistics. In addition the table compares the population of seniors in the assessment areas to the population of senior citizens in Allegheny County.

Table 1. Senior Citizen Population and Economic Status

| | Assessment Area | Allegheny County |
|---|---|---|
| Population over 65 | [illegible] | [illegible] |
| Population below poverty level | [illegible] | [illegible] |
| Per Capita Income | [illegible] | [illegible] |
| Median household income | [illegible] | [illegible] |

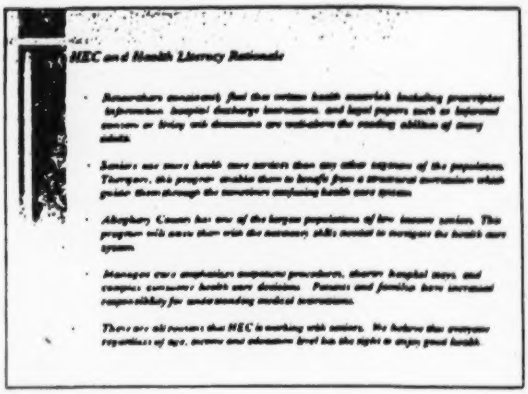


## Advantages of HEC/ALMA Partnership

ALMA's TV411 series appeals to most consumers. Its core curriculum is at a 4th - 8th grade reading level. ALMA materials focus on skills enhancement and everyday problems and include ready-made health segments on video and in print.

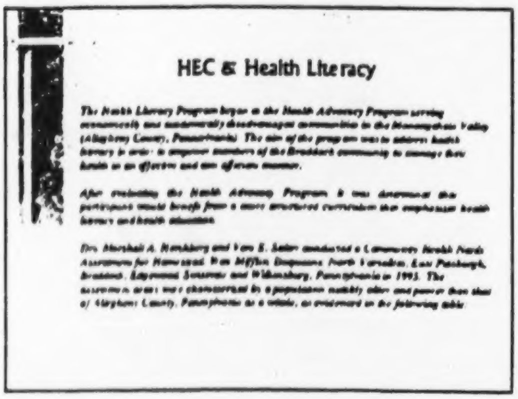
The advantages are:

- HEC is able to remain abreast of current health literacy practice
- ALMA's expertise in functional literacy can be translated smoothly into health literacy
- Collaboration b/w ALMA and HEC staff provides a window into our respective professions
- ALMA provides valuable technical assistance which is often incorporated into HEC program curriculum
- Potential to seek joint funding for health literacy projects



## HEC and Health Literacy Rationale

- Researchers consistently find that written health materials including prescription information, hospital discharge instructions, and legal papers such as informed consent or living will documents are well above the reading abilities of many adults.
- Seniors use more health care services than any other segment of the population. Therefore, this program enables them to benefit from a structured curriculum which guides them through the sometimes confusing health care system.
- Allegheny County has one of the largest populations of low income seniors. This program will assist them with the necessary skills needed to navigate the health care system.
- Managed care emphasizes outpatient procedures, shorter hospital stays, and complex consumer health care decisions. Patients and families have increased responsibility for understanding medical instructions.
- These are all reasons that HEC is working with seniors. We believe that everyone regardless of age, income and education level has the right to enjoy good health.

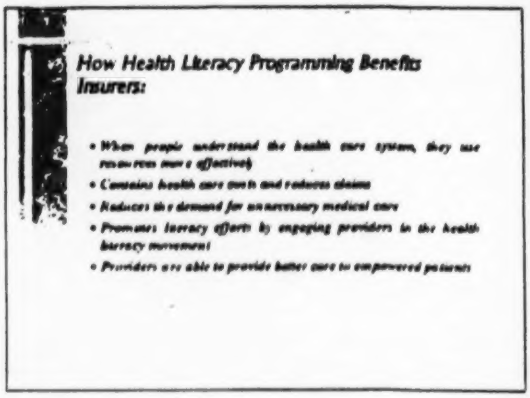


## HEC & Health Literacy

The Health Literacy Program began as the Health Advocacy Program serving economically and academically disadvantaged communities in the Monongahela Valley (Allegheny County, Pennsylvania). The aim of the program was to address health literacy in order to empower members of the Braddock community to manage their health in an effective and cost efficient manner.

After evaluating the Health Advocacy Program, it was determined that participants would benefit from a more structured curriculum that emphasizes health literacy and health education.

Drs. Marshall A. [illegible] and [illegible] E. [illegible] conducted a Community Health Needs Assessment for Homestead, West Mifflin, Duquesne, North Versailles, East Pittsburgh, Braddock, Edgewood, Swissvale and Wilkinsburg, Pennsylvania in 1995. The assessment areas were characterized by a population notably older and poorer than that of Allegheny County, Pennsylvania as a whole, as evidenced in the following table.



## How Health Literacy Programming Benefits Insurers:

- When people understand the health care system, they use resources more effectively
- Contains health care costs and reduces claims
- Reduces the demand for unnecessary medical care
- Promotes literacy efforts by engaging providers in the health literacy movement
- Providers are able to provide better care to empowered patients

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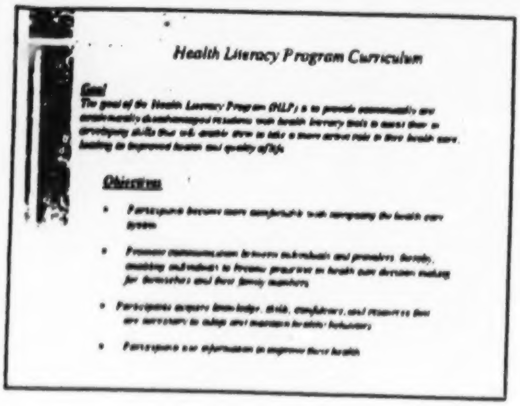


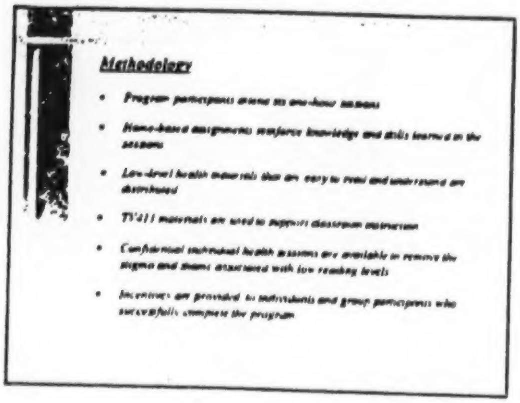
## Health Literacy Program Curriculum

**Goal**

The goal of the Health Literacy Program (HLP) is to provide economically and academically disadvantaged residents with health literacy tools to assist them in developing skills that will enable them to take a more active role in their health care, leading to improved health and quality of life.

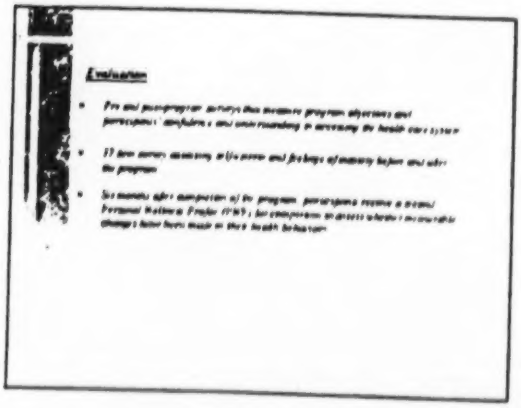
**Objectives**

- Participants become more comfortable with navigating the health care system.
- Promote communication between individuals and providers, thereby enabling individuals to become proactive in health care decision making for themselves and their family members.
- Participants acquire knowledge, skills, confidence, and resources that are necessary to adopt and maintain healthy behaviors.
- Participants use information to improve their health.



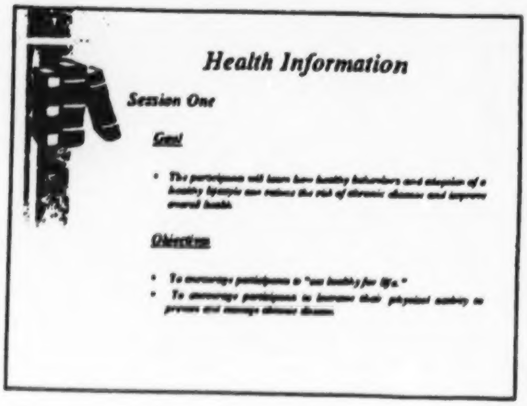
**Methodology**

- Program participants attend six one-hour sessions
- Home-based assignments reinforce knowledge and skills learned in the sessions
- Low-level health materials that are easy to read and understand are distributed
- TV411 materials are used to support classroom instruction
- Confidential individual health sessions are available to remove the stigma and shame associated with low reading levels
- Incentives are provided to individuals and group participants who successfully complete the program



**Evaluation**

- Pre and post-program surveys that measure program objectives and participants' confidence and understanding in accessing the health care system
- [illegible] surveys assessing self-esteem and feelings of mastery before and after the program
- Six months after completion of the program, participants receive a second Personal Wellness Profile (PWP) for comparison to assess whether measurable changes have been made in their health behaviors



## Health Information

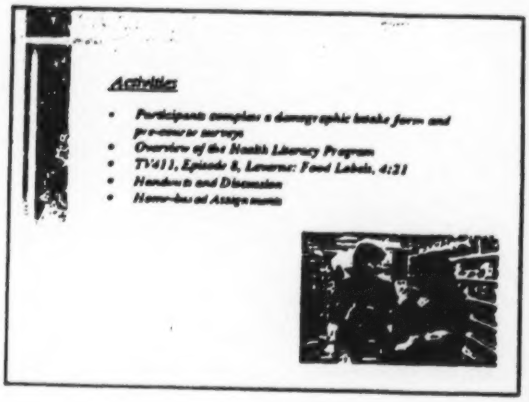
### Session One

**Goal**

- The participants will learn how healthy behaviors and adoption of a healthy lifestyle can reduce the risk of chronic disease and improve overall health.

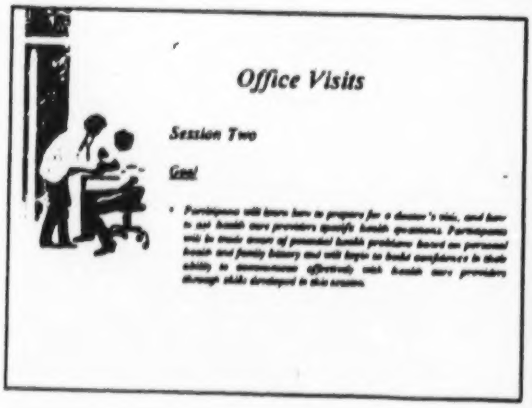
**Objectives**

- To encourage participants to "eat healthy for life."
- To encourage participants to increase their physical activity to prevent and manage chronic disease.



**Activities**

- Participants complete a demographic intake form and pre-course surveys
- Overview of the Health Literacy Program
- TV411, Episode 8, Lessons: Food Labels, 4:21
- Handouts and Discussion
- Home-based Assignments



## Office Visits

### Session Two

**Goal**

- Participants will learn how to prepare for a doctor's visit, and how to ask health care providers specific health questions. Participants will be made aware of potential health problems based on personal health and family history and will begin to build confidence in their ability to communicate effectively with health care providers through skills developed in this session.

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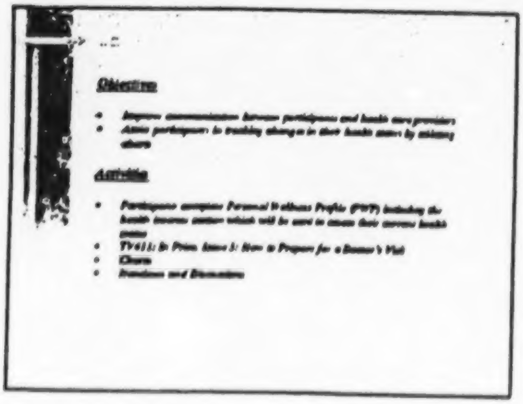
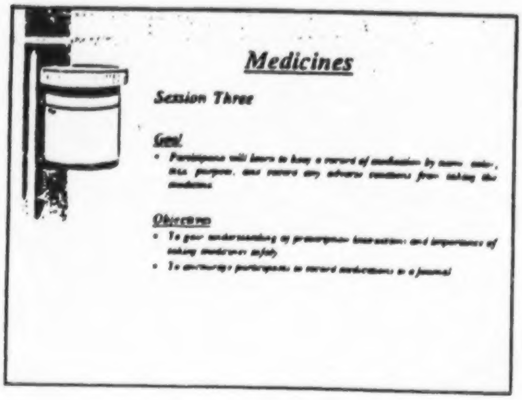


**Objectives**

- Improve communication between participants and health care providers
- Assist participants in tracking changes in their health status by utilizing charts

**Activities**

- Participants complete Personal Wellness Profile (PWP) including the health interest section which will be used to assess their current health status
- TV411: In Print: Issue 5: How to Prepare for a Doctor's Visit
- Charts
- Handouts and Discussions



## Medicines

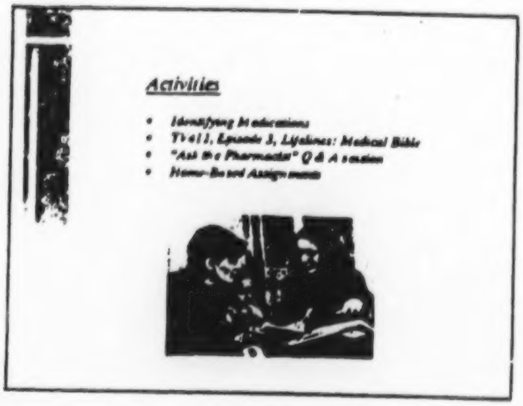
### Session Three

**Goal**

- Participants will learn to keep a record of medication by name, color, size, purpose, and record any adverse reactions from taking the medicines

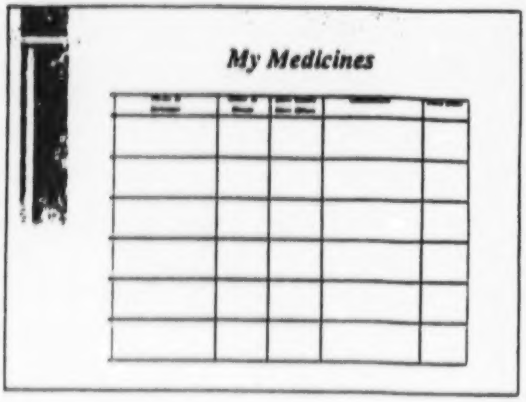
**Objectives**

- To gain understanding of prescription instructions and importance of taking medicines safely
- To encourage participants to record medications in a journal



**Activities**

- Identifying Medications
- TV411, Episode 3, Lifelines: Medical Bible
- "Ask the Pharmacist" Q & A session
- Home-Based Assignments



## My Medicines

| [illegible] | [illegible] | [illegible] | [illegible] | [illegible] |
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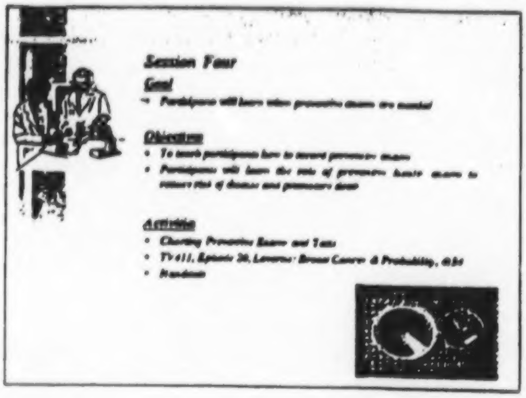


### Session Four

**Goal**

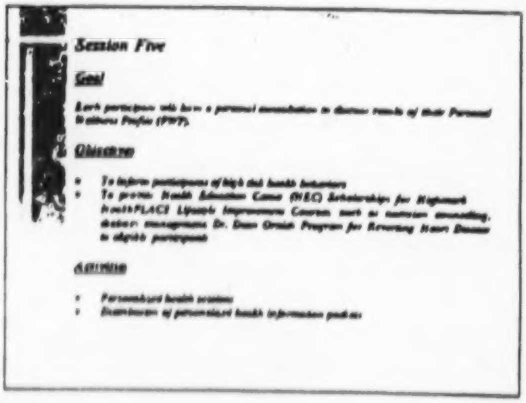
- Participants will learn when preventive exams are needed

**Objectives**

- To teach participants how to record preventive exams
- Participants will learn the role of preventive health exams to reduce risk of disease and premature death

**Activities**

- Charting Preventive Exams and Tests
- TV411, Episode 20, Lessons: Breast Cancer & Probability, [illegible]
- Handouts



### Session Five

**Goal**

Each participant will have a personal consultation to discuss results of their Personal Wellness Profile (PWP).

**Objectives**

- To inform participants of high risk health behaviors
- To promote Health Education Center (HEC) Scholarships for Highmark healthPLACE Lifestyle Improvement Courses such as nutrition counseling, diabetes management, Dr. Dean Ornish Program for Reversing Heart Disease to eligible participants

**Activities**

- Personalized health sessions
- Distribution of personalized health information packets

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# *Health Literacy Program*

## History

The Health Education Center (HEC) Health Advocacy Program (HAP) was piloted in April 1999, in partnership with the Greater Braddock Early Network 4 Kids Child Day Care Center. The program's specific aim was to address health literacy and to empower members of the Braddock community to manage their health in an effective and cost efficient manner.

After evaluating the Health Advocacy Program (HAP), it was determined that the participants would benefit from a more structured curriculum that emphasized health literacy and health education. Data derived from the Health Interest Survey was used to restructure the HAP. The HAP was subsequently replaced with the Health Literacy Program (HLP).

## Introduction and Background

The American Cancer Society (1999) defines "health literacy" as "the capacity to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways "that enhance health." Researchers consistently find that written health materials including prescription information, hospital discharge instructions, and legal papers, such as informed consent or living will documents are well above the reading abilities of many adults. Patients with poor reading skills have difficulty understanding basic medical instructions.

Managed health care today emphasizes outpatient procedures, shorter hospital stays, and complex health consumer decisions. Patients and families have increased responsibility for understanding medical instruction, following procedures, and interpreting health-related information and forms. The health care navigation process can seriously compromise the health and safety of persons with low literacy skills.

## Program Description

The Health Literacy Program (HLP) will serve academically and economically disadvantaged residents. The program will be implemented in the Monongahela and Turtle Creek Valleys of Allegheny County, Pennsylvania. Braddock and Rankin will be the targeted pilot areas in year one. The program will expand in year two to include additional areas of the Monongahela and Turtle Creek Valleys as well as the inner city of Pittsburgh, Pennsylvania. The program will continue in year three to include additional areas of the city of Pittsburgh.

Through the HLP, participants will gain skills that will provide a means for communicating basic health needs. These skills will provide the participant with information to perform necessary health tasks of every day life. Participants will develop the skills to communicate effectively with their health care providers, learn to become confident in navigating the health care system, and understand basic instruction from health professionals. In addition, they will become proactive in health care decision making for themselves and their families.

The program will consist of six one-hour sessions offered at no cost to the participant, and will include group and individual sessions as well as home assignments. Both low-level health materials and TV411 materials will be featured in the sessions. TV411 is an easy-to-use set of study materials composed of videotapes and workbooks. A pre-course survey will be

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administered to program participants upon entrance into the program. The purpose is to gather information about the participants' health knowledge, confidence in navigating the health care system, and their intent to adopt healthy behaviors. The participants will complete selected areas of a health risk assessment to evaluate their health status and to identify risk factors relative to disease prevention.

**Session One** will include health promotion and wellness information. Participants will receive instruction on preparing for a doctor's visit, communicating effectively with their health care provider and reviewing medication guidelines in **Sessions Two and Three. Session Four** will include information about preventive exams and keeping a record of tests and procedures. Health resources, patient rights and confidentiality will be discussed in **Session Five.** Results from the participant's health risk assessment will be reviewed in **Session Six.** A personalized profile will be developed for each participant, and a customized packet of health literature will be prepared according to his or her responses to a health interest survey. A private counseling session will be held with each participant to discuss health risks and to suggest lifestyle changes. For example, participants who desire to quit smoking will be enrolled into a HealthPLACE smoking cessation program.

**Goal**
The goal of the Health Literacy Program (HLP) is to provide economically and academically disadvantaged residents with health literacy tools to assist them in developing skills that will enable them to take a more active role in their health care, leading to improved health and quality of life.

**In order to accomplish the goal the following objectives have been developed:**

- Participants will demonstrate improved confidence in communications with their health care providers.
- Participants will become confident in navigating the health care system.
- Participants will develop skills to use health information effectively.

For more information, please contact Jewel Mosley at (412) 544-8430. The Health Education Center is an affiliate of Highmark Blue Cross Blue Shield.

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*Health Education Center, Inc.*
**120 Fifth Avenue, Suite 1721**
**Pittsburgh, PA 15222-3099**
**(412) 544-7700**

Since 1976, Health Education Center (HEC), a non-profit affiliate of Highmark Blue Cross Blue Shield and beneficiary of the United Ways of Allegheny and Centre Counties, has provided community-based programs that provide health education and disease prevention services to those at risk for poor health education outcomes who are uninsured, underinsured and underserved. HEC will continue its tradition of forging collaborations. HEC will work with community partners to empower individuals to improve quality of life.

HEC provides the following programs at no charge to participants:

- Home Safe Home, a childhood injury prevention program that offers safety inspections, education, and complimentary safety devices to prevent accidents in households with children under age six. Home Safe Home is offered in partnership with various community agencies.

- Not Now!, a teenage pregnancy prevention program that includes intensive case management for girls who receive negative pregnancy test results at clinic sites and features the "Baby Think It Over" program.

- Healthy Families, which helps to empower parents/caregivers of children under the age of eighteen to make positive changes in their health behaviors and thereby improve the health futures of their families. This is accomplished by increasing awareness, knowledge, and access to opportunities to change health behaviors that will ultimately help prevent injury and disease.

- Health Literacy, which helps individuals develop skills to obtain, interpret and understand health literature so that they can improve their health status. Participants learn how to navigate the health care system, and communicate effectively with and understand health instruction from their health care providers.

- HEC Scholarships, which make Highmark HealthPLACE Lifestyle Improvement Courses, such as StartSMART smoking cessation, diabetes self-management, the Dr. Dean Ornish Program for Reversing Heart Disease, Highmark Osteoporosis Prevention and Education (H.O.P.E.) program, weight management, and individual nutrition and exercise counseling accessible to non-Highmark members who lack the financial means to participate in these programs.

**Health Education Center is a 501(c)(3) organization. All contributions are tax deductible. Please consider Donor Option number 804 when contributing to United Way.**

# Health Literacy Program

## Session Overview

**Session One**

Personal information about the participant is gathered. A pre-course survey is completed. Health risk reductions and the benefits of adopting a healthy lifestyle is learned. ALMA TV411 video, Episode 8, "Lifelines: Diabetes", and Episode 3, "Laverne: Food Labels" are viewed.

**Session Two**

Participants learn how to prepare for a doctor's visit and ask health care providers questions. A Personal Wellness Profile (PWP) is administered to assess health status. Participants receive results from PWP during fifth and sixth sessions.

**Session Three**

Keeping a record of medications, taking medicines safely and understanding prescription instructions are discussed. ALMA TV411, Episode 3, Lifelines: "Asthma 911" is viewed. Participants learn to keep a "Medical Bible". Proper tools to measure medicines and taking medicine within specified prescribed timeframes are addressed.

**Session Four**

Participants learn which preventive exams are needed to reduce their risk of disease and premature death and are taught to keep a record of preventive exams that have been performed by their health care provider.

**Session Five**

Participants receive a personal consultation to discuss results from their Personal Wellness Profile (PWP). Areas of high risk are discussed and participants are referred to lifestyle improvement courses.

**Session Six**

Personal consultations continue. Participants learn where to obtain health information. Patient's rights are explored and participants complete post course and self-esteem surveys.

hlp session overview2 revised

ALMA

## WHO IS ALMA?

ALMA (the Adult Literacy Media Alliance) is a new kind of literacy service that harnesses the power of popular media – television, the Internet, print, and video – and combines it with training and a grassroots distribution system to teach adults essential life skills wherever they are.

## THE NEED WE ADDRESS

Some 70 million adults in America cannot compute, read, or write English well enough to effectively seek a job promotion, write a business letter, or help their children with homework. Moreover, fewer than 10% of these adults are able to attend a literacy class due to the demands of work schedules, child-care responsibilities, and long waiting lists.

Most adults in need of literacy education need no convincing that attaining such skills is critical to their own economic viability, as well as to the health, welfare, and academic success of their children. What they do need, however, are literacy services that fit into their everyday lives and suit their learning needs.

## OUR APPROACH

ALMA has gone outside the box of conventional approaches to helping adults improve their basic reading, writing, and math skills by combining several media to meet this end goal.

### TV411

Because 99% of adults in need of literacy education have at least one television and look to the medium as a primary source of information and entertainment, we have created an innovative and powerful television series, **TV411**, that embeds literacy learning in popular television formats.

**TV411** is an Emmy Award-winning, half-hour weekly program with each episode consisting of discrete segments that teach valuable life skills. On **TV411**, you meet Dennis Franz from *NYPD Blue* discussing how to get meaning from a newspaper article, a WNBA star and new mom offering advice on time management, and an *Oprah*-inspired book club series. In addition, you hear stories from real adult learners who share how they acquired the skills to become better parents, employees, and lifelong learners. Not only does this format organize the viewers' experience into manageable nuggets, it also lends itself well to classroom instruction because teachers can pick and choose among the segments.

To date, over 100 PBS stations – including eight of the top ten markets – have committed to broadcasting **TV411**, allowing our program to reach 58% of the households in this country. Ratings for the series have been strong. On one afternoon alone in the New York City area, **TV411** was viewed by an estimated 53,600 people – more than all the adults served by the City's adult literacy programs *in a full year.*

### TV411 in Print

Each episode of **TV411** has an accompanying 12-page, magazine-style workbook which explores in further depth many of the learning concepts presented in the show. **TV411 in Print** deepens the instructional impact of the program by providing opportunities to practice the skills seen in the show. In addition, the workbooks are designed to be a valuable standalone tool, filled with skill-based exercises based on real world situations (e.g., filling out an application, understanding a paycheck, deciphering food labels).

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**TV411 Online**

In order to broaden access to reading, writing, and math learning throughout the country, ALMA has created an interactive website which extends the overall **TV411** curriculum. **TV411 Online** (www.TV411.org) features such tools as interactive lessons, a writing gallery, and activities around the themes of money, parenting, people, and health. In addition, the site has a registered user's portfolio to store learners' work, along with an email Q&A feature to provide users with additional, personalized support.

**Video Series**

The first season of **TV411** has been packaged into a 20-part video series. Together with the **TV411 User's Guide**, **Teacher's Guide**, and **Curriculum Index**, this learning package has proven invaluable for libraries, adult literacy centers, and workplace training programs across the country. The video series is another way of increasing access to literacy education in the community.

**Community Outreach & Training**

Fundamental to the success of **TV411** is the weaving of literacy learning into the fabric of individual communities. Many of our resources at ALMA are devoted to understanding the needs of community-based organizations (e.g., libraries, health clinics, community centers) and helping them develop customized methods of literacy education. In addition, we provide training and technical assistance to teachers and education administrators to help them optimize **TV411** materials in schools and community colleges. Our materials are currently being used in community and education organizations in 31 states.

## DOES ALMA WORK?

All of ALMA's programs and strategies have been based on careful research with learners, teachers, and community organizers. Preliminary evaluation studies on the impact of **TV411** on adult learners indicate that specific literacy skills increase dramatically among users of our material, as do their educational aspirations and their confidence in taking that crucial next step in their educational journey.

## THE ORGANIZATION

ALMA, a project of the Education Development Center, Inc., (EDC) has been developed with support from the Ford Foundation, Wallace-Readers' Digest Funds, other foundations, the Federal government and several State governments. ALMA's founder and Executive Director is Marian Lapsley Schwarz, Ph.D., who created the New York City Adult Literacy Initiative, one of the largest urban literacy programs in the United States. The ALMA national Advisory Board is comprised of a diverse group of experts in adult literacy, television, education, law, technology and community development. The Board is chaired by Augusta S. Kappner, Ph.D., formerly the Assistant Secretary for the US Department of Education and currently president of the Bank Street College of Education in New York City. ALMA's offices are located in New York City.

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